How do 16 -18-year-old adolescents experience and respond to parental terminal illness and death? An Interpretative Phenomenological Analysis

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Declaration

I hereby declare that the work submitted in this dissertation is fully the result of my own investigation, except where otherwise stated.

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Abstract

Approximately 41,000 young people, under the age of 18, are bereaved of a parent each year within the U.K. (Child Bereavement Network, 2014; Winston’s Wish, 2016), and a significant number of these deaths will have been preceded by a period of terminal illness (TI). Adolescents are considered to be particularly susceptible to negative psychosocial outcomes when a parent is unwell (Grabiak, Bender & Puskar, 2007), yet adolescents as a group are less likely to access mental-health services (Reardon, Harvey, Baranowska, O’Brien, Smith & Creswell, 2017). Thus, whilst adolescents of terminally ill (TI) parents may present a vulnerable group, they may also be difficult to engage and subsequently support (Bremner, 2000). There has also been little consideration of how adolescents experience parental terminal illness (PTI), particularly considering their perceptions and experiences of support during this period. This study qualitatively explores the experiences of six individuals who had a parent diagnosed with a TI during late adolescence. Their experiences are explored in terms of their understanding, processing and adjustment to their parent’s TI, both as an individual, and in the context of their wider family and social setting. Their experiences and perceptions of support are additionally explored; considering the role of supportive individuals, services and interventions. Interpretative Phenomenological Analysis was employed to analyse participant data. Participants were individuals who had a parent diagnosed with a terminal illness aged 16-18. Four superordinate themes emerged from the data: 1) ‘Changing family dynamics’ 2) ‘grappling with adolescence and adjustment to loss’ 3) ‘Barriers to feeling/being supported’ 4) ‘Living with the consequences’. Participants relate the profound impact that PTI during adolescence has had and continues to have on their lives. Whilst there are prominent threads of difficulty and distress, elements of positive change and growth are also highlighted. Implications are discussed in terms of service provision and design, including therapeutic recommendations for counselling psychologists and other professionals working with this group.

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Finally, and most importantly, I would like to thank the people who participated in my study. I am truly grateful and humbled that they chose to share their personal and moving stories with me. I hope that I have been able to do their accounts justice in my study and I will remain extremely grateful for the opportunity they have given me.

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Glossary

Abbreviations:

PTI: Parental Terminal Illness
TI: Terminal Illness/Terminally Ill

Definition of terms:

Terminal illness: is an illness for which there is no known cure (World Health Organisation, 2004).

Bereavement: is process of loss, grief and recovery, usually associated with death (World Health Organisation, 2004).

Grief: is a natural multi-faceted response to loss, which comprises emotional, physical, cognitive, behavioral, social, and philosophical components.

Key words:

Terminal illness, parental terminal illness, critical illness, bereavement, grief, loss, children, adolescence, young people, counselling psychology, qualitative research, interpretative phenomenological analysis.

1.0 Reflexive statement

Reflexivity denotes a continual awareness and critical analysis of the impact of the researcher and their subjectivity with regards to all aspects of their research (Kasket, 2013). This requires the researcher to be aware of their relationship to the topic and their presuppositions as well as how these may be actively managed from the pre-research stage and throughout the research process (Finlay, 2002). Therefore, it has been important for me to consider my relationship to the topic at hand and any potential impact this relationship may have on my research.

When first conceiving this research project I was a first-year trainee on the doctorate in counselling psychology. However, my interest in grief and loss stems back to my teenage years, from when my mother passed away from cancer. Several years later, as part of my psychology undergraduate degree, I was tasked with completing an extended essay on a chosen topic and decided to produce a review of some of the prominent theories of grief and loss. I recall considering how theories, such as stage/phase models might prove useful and normalizing for some people, however may also raise concerns for those who do not feel that they “fit” within the models’ categories. Could such models lead individuals to feel that they are not grieving in an appropriate way? And could the grief responses of these individuals potentially be pathologized if they do not appear to fit within what are presented by these more traditional perspectives as “normative” grief processes?

My interest in bereavement, grief and loss followed into my postgraduate study. However, as a trainee counselling psychologist I completed placements in two different general settings, including Improving Access to Psychological Therapies (IAPT) and a counselling service within a GP practice, and two specialist placements within an Eating Disorders Service (EDS) and a psychological service for older adults. I was nonetheless struck by, how across these diverse settings, issues relating to loss and bereavement appeared largely ubiquitous. Subsequently, it has been essential for me to consider my theoretical understanding of grief and loss and how it can inform working with diverse client groups within various settings. I consider it to be through my personal experiences, undergraduate study and trainee placements that my interest in understanding the experiences of those encountering loss has evolved, and I have sought to question how practitioners might go about meeting the needs of the grieving.

Furthermore, my personal and professional experiences have demonstrated that difficulties relating to bereavement, grief and loss are not just relevant immediately after a close death.

Rather, bereavement can present a challenging and ongoing process of adjustment which is not necessarily indicative of a pathological response. Also, the events leading up to bereavement may be of significance. How did someone die? Was the death anticipated? Was there suffering? In an attempt to further understand the complexities of pre-bereavement periods, I came across the Anticipatory Grief literature. Despite the vast body of work in this area, there appeared to be many definitional, theoretical and empirical inconsistencies. Perhaps most notable, is whether an anticipated death might be more facilitative of positive adjustment than sudden death. In this regard, recent findings suggest that young people may find periods of terminal illness more stressful than the bereavement which follows. Yet, there are few studies, focusing on the experiences of young people during this period and subsequently what may be of help or even hindrance to them.

When I began my literature review, my assumptions, presuppositions and experiences influenced the way I approached the topic. Despite attempting to bracket these off, I found myself searching for literature which matched my perspective. Particularly, stemming from my undergraduate study, I held assumptions about the usefulness and applicability of theories and models of grief; believing them to be inflexible and congruent with a “one size fits all” approach. Yet, through my literature search I found further models of grief that appeared to offer more individualized conceptualizations of grief. Moreover, I began to view traditional theories less prescriptively, and subsequently less critically.

However, whilst more contemporary literature and research pertaining to grief and loss, espoused a greater appreciation for individual difference and experience, there appeared to be a lack of evidence-based theories relating to the bereavement experiences of children and adolescents. Moreover, the empirical research demonstrated a disproportionate focus on firstly adults and more recently children. Whilst I had worked with clients across the life span, I had not worked with adolescents and working with young people formed little part of the teaching and training on the doctoral program. This led me to not only reflect on why adolescents may feature less prominently in literature and research but also whether counselling psychologists were well placed to contribute to knowledge in this area.

My choice of counselling psychology over another applied discipline was largely guided by the philosophical underpinnings of the profession, such as empowering and respecting clients, facilitating growth and helping people work and live up to their potential. I noted that these premises appeared to align with a more recent focus in the grief literature on acknowledging the uniqueness of individual experiences of loss, and also in appreciating and promoting human resilience. Upon reflection, I felt that focusing on adolescents’ experiences of grief and loss may be empowering, giving them a voice in the literature. It is therefore my hope that that I will not only make a unique contribution to research in this area, but that I might also elucidate the potentially unique contribution counselling psychologists may be able to make; not only in working with grief and loss, but also in working with young people. Finally, I hope that this research may inform those working with this population, bringing further understanding and consideration to the experiences and needs of adolescents with terminally ill parents.

2.0 Introduction

Approximately 41,000 young people, under the age of 18, are bereaved of a parent each year within the U.K. (Child Bereavement Network, 2014; Winston's Wish, 2016), and a significant number of these deaths will have been preceded by a period of serious illness. When illness becomes incurable/terminal, it can present significant stressors for family members; particularly young people (Thastum, Johansen, Gubba, Olesen & Romer, 2008). However young people's experiences of parental terminal illness (PTI) have received limited attention in the literature and research (Christ & Christ, 2006; Philips, 2014).

Adolescents, in particular, are considered to be the most susceptible to negative psychosocial outcomes when a parent is unwell (Grabiak, Bender & Puskar, 2007) and it has been suggested that PTI may hinder normative developmental processes and lead to long-term psychological consequences for this group (Ohannessian, 2007; Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). Yet, adolescents, as a distinct group, have historically been neglected in bereavement literature and research, and there are fewer resources available to them (Dunning, 2006). It has also been reported that only a minority of adolescents with mental health problems access treatment (Reardon, Harvey, Baranowska, O'Brien, Smith & Creswell, 2017), however the reasons for this are not well understood. Thus, whilst bereaved adolescents, and those with terminally ill (TI) parents may present a vulnerable group, they may also be difficult to engage and subsequently support (Bremner, 2000).

Psychologists and practitioners from health, education and social care have a significant role in providing support for young people facing bereavement, and their families. It is therefore important that they understand the individual and collective challenges that may be encountered and what types of support may be of benefit. Whilst the role of counselling psychology is less prominent in working with children and adolescents than other applied disciplines, such as educational and clinical (Davy & Hutchinson, 2010), the discipline may have much to offer; in terms of its core principles and values. Individual subjective experience is central to counselling psychology (Woolfe, Dryden & Strawbridge, 2003), and may lend to eliciting the lesser-heard narratives of adolescents facing bereavement. Moreover, the discipline's emphasis on "facilitating growth and the actualisation of potential" (Cooper, 2009, p.120) may be particularly relevant in working with adolescents on the cusp of adulthood; who alongside adverse circumstance such as PTI and bereavement, confront developmental challenges and choices, which may irrevocably impact their future. Furthermore, one of the most significant challenges in working with adolescents, may be engaging them (Bremner, 2000), thus counselling psychologists continued focus on building and maintaining a strong therapeutic relationship with clients (Strawbridge & Woolfe, 2010) may further lend to work with this group.

Whilst children and young people’s mental health has been highlighted in recent times (Fonagy & Clark, 2015), with a focus on the potential benefits of early and effective intervention (DoH, 2011), few studies have considered the circumstances of adolescents of TI parents, and how this potentially vulnerable group may be supported and equipped for present and future stressful life events (APA, 2014). This literature review will therefore provide a rationale for the present study through an exploration of relevant literature and research concerning PTI and bereavement during adolescence. It will also consider adolescent support-seeking and the provision of bereavement support in the U.K, before reflecting on the role and relevance of counselling psychology to work in this area.

3.0 Literature review

3.1 Theories of Grief and Loss

Traditional perspectives on death, dying and bereavement stem back to Freud's seminal text On Murder, Mourning and Melancholia (Freud, 1917). Within this text, Freud poses the necessity of relinquishing ties to the deceased, via detachment or decathexis, emphasizing the role of grief work in leading the bereaved to move on and begin to form new significant relationships (Freud, 1917). Asserting an end-point of grief, by way of detachment, resolution, reorganisation or recovery (Lindermann, 1944; Parkes, 1971; Bowlby, 1980; Kubler-Ross, 1969) remained pivotal in subsequent prominent theories of grief and loss.

Bowlby (1980) also adopted a linear model of grief whereby the bereft would initially experience numbness, then yearning and searching, disorganisation and despair, before concluding with reorganisation. These stages were based on the premises of Attachment Theory (Ainsworth & Bowlby, 1954; Bowlby, Ainsworth, Boston & Rosenbluth, 1956) which considers the affectional bonds or ties, formed initially between child and parent and subsequently between adult and adult (St. Clair, 2000). Attachment theory emphasizes the quality of the relationship, initially formed between child and primary caregiver; which assumes a pivotal role in the child's development (Ainsworth, 1969; Bowlby, 1980). Internal working models are formed during the first stages of life, through caregiver interactions. Based upon which, the child begins to form a model of self as being more or less deserving of love. A model of other is also formed, as to whether the other is perceived as being attentive and sensitive to the child's needs (Bowlby, 1988).

As the security of attachments influences the maintenance of relationships, consequently, the ending of relationships (i.e. bereavement) are similarly implicated (Hazan & Shaver, 1987). Thus, attachment theory positions grief as a form of separation anxiety (Bowlby, 1969, 1980); resulting from the enduring disruption of an attachment bond (Mancini & Bonanno, 2009). Variation in terminology is apparent across research domains (Stroebe, Schut & Stroebe, 2005), however based on the work of John Bowlby (Bowlby, 1969, 1980), Mary Ainsworth (Ainsworth, 1982, 1985) and Mary Main (Main, Kaplan, & Cassidy, 1985), attachment styles are widely presented in terms of; secure, dismissive, preoccupied, and disorganised (Shaver & Tancredy, 2001). According to Bowlby (1980), individual responses to loss are thus determined by these individual attachment styles; whereby those securely attached would experience better post-bereavement outcomes. For those insecurely attached, Bowlby's (1980) final stage of reorganisation may not be reached as the individual may be unable to incorporate the bereavement experience into his or her mental model of self and others (Beverung & Jocobvitz., 2016).

Elizabeth Kubler-Ross (1969) presents a further model of grief and loss, in *On Death and Dying*. The "Five Stages of Grief" (Kubler-Ross, 1969) encompass: denial, anger, bargaining, depression and acceptance, and were initially developed for those diagnosed with a terminal illness, before being expanded to cover post-bereavement grief and other significant losses, experienced throughout the life-course. Despite critique, for the seeming rigidity of the model, Kubler-Ross (1969) posits that the stages are not intended to be static and sequential. Rather they may occur at different times and last for indeterminable durations (Kubler-Ross, 1969).

Stage theories and models of grief are taught and espoused in medical, professional and varying contexts, despite a historical lack of empirical research attesting the validity and applicability of these theories for the bereaved (Bonanno, 2007). However, results from a longitudinal cohort study, carried out by Maciejewski, Zhang, Block and Prigerson (2007), seemingly offer support for some common constructs of stage theories of grief (employing five grief indicators: disbelief, yearning, anger, depression and acceptance). Yet Bonanno (2007) rebukes that the measurement of stages may be difficult and unreliable; and in Maciejewski et al.' (2007) study, only one questionnaire item was used to assess each construct.

In a similar vein of critique, Bonanno, Wortman, Lehman, Tweed, Haring, Sonnega, Carr and Nesse (2002) argue that much of the bereavement research has substantial methodological and conceptual limitations. Moreover, results from their longitudinal study suggest that grief responses may vary considerably from person to person, and as such, traditional notions around what constitutes a "normative" grief response may require reconsideration. As the range of individual responses to loss may vary significantly from person to person, without these variations being indicative of a clinical or pathological response to loss. The study included 205 participants who were assessed for depressive (Center for Epidemiologic Studies Depression CES-D Scale) and grief symptoms (Beck Bereavement Index, Present Feelings About Loss Scale, Texas Revised Inventory of Grief) prior to, six and eighteen months post-loss.

Given their continued prominence, stage models of grief persist in drawing criticism, and in a recent paper Stroebe, Schut and Boerner (2017) further attest the lack of sound empirical evidence, conceptual clarity and explanatory potential associated with stage models of grief.

Moreover, they argue that the models also lack practical utility in the design and targeting of interventions and the identification of those most vulnerable; which bears particularly relevance given the inclusion of “persistent complex bereavement-related disorder” as a category for further research in The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013).

However and contrastingly, Stroebe and Schut (1999) offer a different conceptualization of grief and loss through their Dual Process Model (DPM), which aims to further capture the complexity and duality of grief. The DPM suggests that there are two central aspects in adapting post bereavement, the loss orientated and restoration orientated (Stroebe & Schut, 1999). Whilst the loss orientation refers to dealing with and processing the loss experience itself, the restoration-orientation aspect depicts coping processes, which involve adjusting to the changes brought about by the loss (Stroebe & Schut, 1999). For example, taking on the tasks previously carried out by the deceased, managing with day-to-day life and forming a new identity without a loved one. Subsequently, it could be argued that the DPM moves beyond its predecessors in demonstrating the complexity and multifaceted nature of grief. Moreover, it addresses the oscillation of emotions and experiences following close bereavement and accounts also for social and psychological processing as well as individual difference.

Somewhat similarly, is Dr. Linda Machin’s (2001) Range of Response to Loss (RRL) Model, which as intimated by its title, emphasises the enormous range of individual responses to loss (Machin, 2001, 2014). Derived from clinical practice and research, the RRL model acknowledges variability in grief responses, presented along two axis; allowing for a more qualitative understanding of the unique grief experiences of the individual. The intersecting axis of the model, present a range from overwhelmed to controlled grief reactions, and coping responses ranging from vulnerable to balanced/resilient (Machin, 2014). Notably, the RRL categories are consistent with other contemporary theories and constructs of grief (Horowitz, Wilner & Alvarez, 1979; Martin & Doka, 2000). Thus, whilst the premises of the model are grounded in language used by clients in a therapeutic setting, parallels can be drawn with the DPM (Stroebe, Gergen, Gergen & Stroebe, 1992; Strobe, 1993; Stroebe & Schut, 1999) and the RRL categories relate to the attachment styles posed by Ainsworth (1970) and Bowlby (1980).

The RRL suggests that an individual’s capacity to cope must be understood in the context of their individual resources, pressures and strengths and vulnerabilities; presented on a spectrum of responses spanning from risk to resilience (Machin, 2007). It could therefore be argued that the model poses a useful tool for both understanding and working with individual grief responses, as it facilitates the identification of factors associated with resilience as well as risk/vulnerability. The model also considers the availability and employment of social support, including family and wider social and cultural networks (Rosenblatt, 1993; Machin, 2001), which is less emphasized in more traditional models.

Whilst this is not an exhaustive outline of all theories of grief and loss, those presented have been condensed from a number of sources in an attempt to provide an overview of a number of prominent theories of grief and loss; which were found to most frequently appear in the literature. However, it should be noted that numerous other theories and models exist in this area, including: Worden's tasks of mourning (Worden, 1983), continuing bonds perspectives (Klass, Silverman and Nickman, 1996) and meaning reconstruction (Neimeyer & Anderson, 2002), amongst others, which may all be referenced in relation to bereavement and bereavement care.

However, it could be argued that overall, there appears to be a dearth of qualitative and quantitative empirical research providing a sound base for existing theories of grief and loss, and Bonanno (2007) particularly argues that traditional models, largely based on case studies and studies comprising methodological and conceptual limitations, remain a central aspect of what is understood about grief. Yet, it could also be argued that traditional theories and models have been frequently misconstrued and too ardently critiqued. Parkes (1998) poses that stage models of grief were not designed to be prescriptive and authors have continued to emphasise that they do not pose linear or sequential stages but rather an understanding of how individual grieving may fluctuate and transition over time. When adopting this perspective and considering traditional models alongside the more contemporary, there is arguably an overarching element of a range of individual and fluctuating responses to loss, framed within specific developmental, psychological, social and cultural contexts.

However, if there are a range of individual responses to loss, which interrelate with developmental, psychological, social and cultural contexts, should not further consideration be given to the experiences of children and adolescents? Whose developmental, psychological and social contexts might be significantly different to those of adults? Rolls (2011) argues that young people's experiences of loss should be given greater consideration. She contends that prominent theories and models primarily centre on adult experiences, and the nature of childhood bereavement and is trajectory is not fully understood (Rolls, 2011).

In the relative absence of theories and models specific to young people's experiences of grief and loss, Rolls and Payne (2007) further assert that the premises of existing theories and models are borrowed and adapted for use with children and young people (Rolls & Payne, 2007). However, in doing so, it could be argued that an assumption is being made that children and young people experience loss in the same way as adults. Perhaps, also, in tailoring theories and models for young people, there may also be a failure to capture any distinct challenges or complexities associated with losing a loved one during childhood or adolescence (Balk & Corr, 2001) and subsequently, opportunities for understanding and adequately responding to their potentially distinct needs may also be missed.

3.2 Young people in bereavement literature and research

Children and young people's bereavement experiences have also been largely underrepresented in bereavement literature and research more widely (Garmezy & Masten, 1994) and yet it has been argued that the death of a parent during childhood or adolescence is a stressful event (Lawrence, Jeglic, Matthews & Pepper, 2006; Marwitt & Carusa, 1998) that has been linked to depression, anxiety, hopelessness and suicidal ideation (Clements, Focht-New & Faulkner, 2004; Latham & Prigerson, 2004; Worden & Silverman, 1996). Immediately following parental death, children will experience a period of bereavement, including periods of sadness and more intense grief responses (Kranzler, Shaffer, Wasserman & Davies, 1990). Eighteen months following bereavement, children are considered to be, in the majority, well-adjusted and score comparably to national norms on measures of anxiety and depression for non-bereaved children (Kalter, Lohnes, Chasin, Cain, Dunning & Rowan, 2003). However, a smaller number of children and adolescents, will experience more pervasive difficulties in adjusting to the death of a parent and the longevity and intensity of responses may be associated with Persistent complex bereavement-related disorder (5th ed.; DSM–5; American Psychiatric Association, 2013; Bryant, 2014), which references the long-term emotional difficulties which persist following bereavement and may lead to associated psychological diagnosis and symptoms; such as depression and anxiety (Rapael, Cubis, Dunne, Lewin & Kelly, 1990).

Furthermore, a parent's diagnosis of a critical or TI creates social and psychological pressure for young people (Philips, 2014) and children and adolescents are significantly impacted by a parent's illness in all areas of functioning; particularly emotional well-being (Visser et al., 2004). PTI may also lead to long-term psychosocial outcomes for children and adolescents (Huizinga, Visser, Zelders-Steyn, Teule, Reijneveld & Roodbol, 2011).

Yet, it is adolescents as a group, who are considered to be the most susceptible to negative psychosocial outcomes when a parent is unwell (Grabiak et al., 2007).

Adolescence is frequently presented as a challenging stage of life, marked by significant physiological and psychological growth. Erik Erikson defined adolescence as a period of "identity vs. role confusion" where adolescents are engaged in the task of defining their identity and their place within society (Crain, 2000). In beginning to form a personal identity distinct from their parents, adolescents begin to separate from their parents and turn towards their peers for acceptance (Polmear, 2004). As adolescents increasingly separate from their parents, conflict is typically experienced in the parent-child relationship. Thus, when an adolescent's parent becomes ill or dies they may struggle with feelings of guilt and remorse (Marwit & Carusa, 1998). Adolescents may also feel conflicted in their desire for independence alongside a desire to remain within the family in order to both provide and gain support.

Furthermore, in accordance with Jean Piaget's theory of intellectual development, adolescents are at a stage of "formal operations" where they become increasingly capable of independent and hypothetical thinking (Hurd, 2004). Thus, whilst younger children are primarily concerned with the present, adolescents may look to the future and begin to think in more abstract ways (Crain, 2000). Owing to these more advanced cognitive and empathetic capacities, adolescents are also more aware of present and future losses than younger children, as well as being more attuned to their loved one's physical and emotional pain (Christ, Seigel & Sperber, 1994; Kristjanson, Chalmers & Woodgate, 2004). Beasley and Beasley (2002), as cited in Allen (2002), therefore argue that "adolescents may be more prone to negative consequences of bereavement because, unlike children, they are no longer protected psychologically by immature cognitive skills and concrete thinking that could buffer them from the full impact of bereavement" (Allen, 2002, p. 63).

Children's perceptions and understanding of death changes as they develop cognitively and socially, and whilst adolescents are developmentally equipped to understand the biological, social and psychological aspects of death, they view it as something that happens to others; disregarding their own and their loved ones' mortality (Pettle & Britten, 1995). For this reason, experiencing significant bereavement may be acutely difficult for adolescents, as they face the reality of their loved one's death as well as their own future mortality (Nolen-Hoeksema & Larson, 1999).

As developmentally adolescence is a time of significant personal and social transitions, when a parent becomes unwell, these processes of change and growth may be side-lined; posing a threat to normal development (Ohannessian, 2007). Losing a parent may also negatively impact the adolescent's emerging sense of self and may inhibit the natural process of separation that typically occurs between adolescents and their parents (Sussillo, 2005). Moreover, adolescents may be compelled to accept additional responsibilities within their family, such as cooking, cleaning and taking care of younger siblings which those younger may not be able or expected to undertake.

Yet, despite the potentially distinct challenges associated with parental illness and bereavement during adolescence, rarely in the literature and research, is a clear distinction made between children and adolescents (Christ et al., 1994); rather the terms "child", "children" and "childhood" are frequently used to refer to those aged from 0-18 years (Corr & Balk, 2010; Rolls & Payne, 2007). Thus, Philips (2014) positions that adolescents constitute a vulnerable population who are often overlooked by researchers and healthcare professionals.

3.3 Parental terminal illness during adolescence

Whilst adolescents may constitute a vulnerable population in relation to parental illness and bereavement, findings from existing research (E.g. Christ et al., 1994; Philips, 2014; Philips & Lewis, 2015; Rainville, Dumont, Simard & Savard, 2012) further indicate that the end stages of a parent's illness may be a particularly vulnerable time for adolescents. Yet there has been limited research on adolescents' experience of and adjustment to PTI (Philips, 2014). Of the studies that have been conducted, most focus almost exclusively on cancer (Davey, Gulish, Askew, Godette & Childs, 2005; Osborn, 2007; Pederson & Revenson, 2005; Philips & Lewis, 2015; Sears & Sheppard, 2004; Spira & Kenemore, 2000; Stiffler, Hasse, Hosei & Barada, 2008; Stoppelbein, Greening & Elkin, 2006; Weaver, Rowland, Alfano & McNeel, 2010) and only a limited number of studies specifically focus on the terminal stage of illness. This is despite illness severity and reoccurrence being associated with adolescent adjustment (Grabiak et al., 2007). Additionally, many of the studies conducted in this area have included a wide age range of participants (Birenbaum, Yancey, Philips, Chand & Huster., 1999; Christ et al., 1994; Compas, Worsham, Ey & Howell., 1996; Saldinger, Cain & Porterfield, 2003; Welch, Wadsworth & Compas., 1996); despite increased age being associated with increased levels of psychological distress (Rainville et al., 2012) and reduced Health-Related Quality of Life (HRQoL) (Kuhne, Krattenmacher, Bergelt, Ernst, Flechtner, Fuhrer, Herzog, Klitzing, Romer & Moller, 2012).

Furthermore, in a recent systematic review of quantitative, qualitative and mixed methods publications between 2000 and 2013 carried out by Philips (2014), eighteen studies were found which considered adolescents (aged 12-18 years) of a parent with an incurable or terminal cancer diagnosis, and of these studies, only four were found to focus exclusively on adolescent experiences (Philips, 2014). Two of these were quantitative studies, examining psychological distress (Rainville et al., 2012) and psychosocial adjustment and health-related quality of life (Kuhne et al., 2012). One of the qualitative studies adopted a constructionist grounded theory approach to discern interaction patterns in families with adolescent children (Sheehan & Draucker, 2011) and the final early qualitative study explored characteristic psychosocial reactions to a parent's terminal illness in 120 children and adolescents across a broad age range from 11-17 years (Christ et al., 1994). Thus, Philips' (2014) systematic review, highlights a seeming dearth of research focusing specifically on adolescent's experiences of PTI.

3.3.1 Difficulty and distress following a terminal diagnosis

The earliest of the aforementioned studies, outlined in Philips' (2014) review, was conducted by Christ et al. (1994), and identified five common problems and concerns confronted by adolescents of TI parents. Empathy for their parents' suffering, increased involvement with the ill parent, household responsibilities, influence of the parental relationship and guilt (Christ et al., 1994). Furthermore, the authors describe how the majority of the adolescent participants were able to speak openly regarding the circumstances of their parent's illness and treatment, however experienced greater difficulty in discussing their emotional reactions and responses to their parent's illness. Such difficulties were attributed to the adolescents' advanced cognitive capacities, which allowed them to comprehend the severity of their parent's illness and its impacts on their present and future life; which may not be the case with younger children. Unfortunately, the qualitative method employed for the study is not outlined, making it difficult to assess the methodological and empirical strengths and limitations of this study, and it is also noted that this study included a wide age range of participants (aged 11-17 years) without significant exploration of potential variations therein.

However, a subsequent study, conducted by Siegel, Karus and Raveis (1996), similarly highlights stressors associated with PTI for young people. Results indicate that anxiety and depression may be higher during the terminal phase of parental illness, than 7-12 months following parental death, suggesting that periods of TI may be more distressing than earlier stages of illness and potentially following actual loss. Similar findings are also intimated by Saldinger et al. (2003), who found PTI to be associated with traumatic stress responses in participants (aged 6 to 16 years). Results of this qualitative study, which included 58 parentally bereaved young people, suggest that exposure to the physical, emotional and psychological deterioration of a parent may be one of the greatest challenges facing young people impacted by PTI (Saldinger et al., 2003). Moreover, "traumatic stress" responses (Saldinger et al., 2003, p.168) were also associated with exposure to the knowledge of impending death and the anxiety associated with this knowledge and a "secondary traumatic stress" (Saldinger et al., 2003, p.168) was depicted in watching family members succumb to dread and anxiety as death approached. The authors of this study assert young people's unique vulnerability to traumatic stress and the adverse impacts of PTI during this period are subsequently inferred. However, the study again included a wide age-range of participants and the potential relevance of other factors (such as parent-child relationships or the presence of support), which may influence young people's responses to PTI, were not discussed.

Notably, Grabiak et al. (2007), in their meta-analysis of published studies and literature reviews pertaining to adolescents of cancer patients, critique studies which include participants spanning a wide range of ages, due to the potential differences therein; rather they advise researchers to "include only pre-school children, school-age children, or adolescents in their study" (Grabiak et al., 2007, p. 134). In keeping with this recommendation, results from their literature review, suggest that adolescents (defined as: early 10-14 middle 15-17 and late 18-20) may be particularly vulnerable during periods of parental cancer, however it should be noted that studies reviewed included those at different stages of illness (not specifically the terminal phase).

However similar findings have more recently been reported. In a quantitative study exploring psychological distress among adolescents living with a parent with advanced cancer, results suggest that late adolescents in particular, may experience significantly higher levels of distress than the general population, and even younger adolescents (Rainville et al., 2012). As part of the study, twenty-eight adolescents aged 12 to 18 years with a parent with advanced cancer were evaluated for psychological distress using the Indice de distresse psychologique de Sante Quebec (IDPSQ-14) and results indicate increased levels of psychological distress, on all four dimensions (depressive state, anxious state, cognitive problems and irritability), were experienced by adolescents living with a parent with advanced cancer. Further analysis demonstrated no significant differences between controls and adolescents aged 12 to 14 years, however showed significant differences in adolescents aged 15 to 18 in comparison to their peers. Notably the sample size is particularly small in this study and arguably more suited for a qualitative than quantitative analysis. However, somewhat similar findings were reported in a further quantitative study, carried out by Kuhne et al. (2012), whereby older adolescents, of parents with advanced illness, demonstrated distinctly low levels of health-related quality of life (HRQoL).

Alongside the apparent difficulties associated with a parent being diagnosed with a TI; such as the diagnosis itself, symptoms, treatment and repercussions, several studies highlight challenges associated with changing household roles and responsibilities (E.g. Christ et al., 1994; Jantzer, Grob, Stute, Parzer, Brunner, Willig, Schuller-Roma, Keller, Herzog, Romer & Resch, 2013; Melcher, Sandell & Henriksson, 2015); specifically how adolescent children may adopt enhanced roles of responsibility at home. In one such recent study, Melcher et al. (2015), interviewed ten teenagers (aged 14-19 years), and analysed transcripts using content analysis to explore how teenagers adapt to responsibility when a parent is dying. Themes of “understanding the illness and preparing for the loss”, “feeling and taking responsibility for parents and family life” and “feelings of loneliness and support” emerged from the data (Melcher et al., 2015, p.3). Participants reported being significantly impacted by their parent’s illness, however demonstrated significant compassion and maturity in taking care of their parents and siblings to maintain family life. Yet, whilst the adolescents spoke about their role in providing support, they also expressed a need for support. In this regard, parents were found to be their major source of trust, safety and comfort. However, the authors caution that a lack of adequate information or support may leave adolescents particularly vulnerable to less desirable outcomes following bereavement (Melcher et al., 2015).

3.3.2 Informing and communicating with adolescents about terminal illness

The role of information-sharing and communication is further highlighted in much of the literature and research in this area. For example, there is evidence in the literature to suggest that parenting quality affects child and adolescent adjustment to parental illness (Sigel, Perry, Robbins, Gagne & Nassif, 2003) and positive parental relationships prior to diagnosis may help adolescents adapt to changes brought about by illness (Christ et al., 1994). Specifically, Kennedy and Lloyd-Williams (2009) position that open communication between parents and children may be of particular significance; both in promoting affective coping and enhancing parent-child relationships.

Similar findings are suggested in Sheehan, Draucker, Christ, Mayo, Heim and Parish’s (2014) qualitative study, exploring how adolescents are informed about their parent’s terminal illness. Twenty-two families with adolescents, aged 12-18, with a parent in a hospice completed the study, and individual interviews were conducted and analysed using constant comparison methods. Results suggest that adolescents are informed about PTI in different ways, largely dependent on existing communication patterns within families (Sheehan et al., 2014). However, parents appeared primarily, to want to ease their children’s burden and distress when informing them about the diagnosis. Yet, adolescents themselves demonstrated the greatest receptiveness to more open and informative communication styles (i.e. “measured telling”) as they perceived that they were being kept fully informed. Sheehan et al. (2014) subsequently highlight the difficulties parents, caregivers and healthcare providers may experience in communicating effectively about PTI with adolescents.

Prior research has proffered similar concerns; demonstrating how parents may struggle to initially inform and continue to communicate about their advanced illness with their children (E.g. Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; Turner, Clavarino, Yates, Hargraves, Connors & Hausmann, 2007; Turner, Kelly, Swanson, Allison & Wetzig, 2004). Research findings suggest that parents may struggle deciding which information to convey, when to present it and what language to use (Houldin & Lewis, 2006; Turner et al., 2007; Turner et al., 2004) and parents may also wish to maintain hope, without distorting the truth (Turner et al., 2007).

Despite the challenges parents may face in speaking about PTI with their adolescent children, and the importance effective communication may hold for adolescents in terms of coping and adjustment, the literature suggests that parents may receive little guidance or support from healthcare professionals with regards to communicating with their children about their illness (Kennedy & Lloyd-Williams, 2009; Turner et al., 2007; Turner et al., 2005). Moreover, there appears to be a death of research conducted from the perspective of adolescents themselves (Beale, Sivesind & Bruera, 2004; Bugge, Helseth & Darbyshire, 2008; Kennedy & Lloyd-Williams, 2009); namely, exploring what information they perceive as being integral and how this information might best be conveyed.

3.3.3 Adapting and coping

Alongside the importance of information-sharing and communication, adolescent coping and adaption has also been underlined within existing literature and research. In fact, in

Grabiak et al.’s (2007) meta-analysis of studies published between 1966 and 2006, examining the impact of parental cancer on adolescents, “ways of coping” (Grabiak et al., 2007, p. 127) was identified as a recurring theme within the literature. The concept of coping is broadly defined in the study by Lazarus (1993, p. 237) as “ongoing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” and results from Grabiak et al. (2007), suggest that adolescents may use a variety of different coping skills and mechanisms, including “problem-focused coping” (Grabiak et al., 2007, p.129); which may involve asking questions, reading about the illness and increasing involvement in practical and domestic tasks, “emotional-coping” (Grabiak et al., 2007, p.129), depicted as avoiding thinking about or talking about the illness and “dual-focused coping” (Grabiak et al., 2007, p.129) which encompassed use of both strategies. Additional elements associated with adolescents’ ability to cope with parental illness, included family, friends and the school environment, which were described as providing a beneficial sense of normality (Grabiak et al., 2007). Again, it should be noted that a number of the studies compiled as part of Grabiak et al.’s (2007) review, included participants spanning a wide range of ages, and additionally parents at differing stages of illness; not specifically the terminal phase.

Similarly, to findings from Grabiak et al. (2007), other prior studies (E.g. Herman-Stahl, Stemmler & Peterson, 1995) have stressed the importance of coping styles in adjusting to parental illness and death. Namely, active-coping, support-seeking and avoidant-coping have been outlined (Herman-Stahl et al., 1995). Active coping styles are depicted by Ebata and Moos (1991) as acknowledging the event (i.e. diagnosis or bereavement), finding ways of resolving difficulties and incorporating the event into their lives. Such active coping styles are potentially facilitative of positive adjustment, as Herman-Stahl et al. (1995) suggest that adolescents displaying active coping styles are less likely to experience depressive symptoms. A similarly adaptive coping style, outlined by Herman-Stahl et al. (1995) is that of support-seeking; whereby adolescents draw on family, peers and those in their environment to gain the support they need. Demonstrating the potential usefulness of this approach, Lawrence (1996) found that children who sought support following a parent’s death were more likely to have higher self-esteem, less behavioural problems and fewer symptoms associated with depression; in contrast to those employing other coping styles. However, and contrastingly, adolescents may also demonstrate avoidant coping styles (Herman-Stahl et al., 1995); typified by failing to acknowledge a significant event, pretending it did not happen or downplaying its impact. Whilst avoidant coping styles are likely to improve an individual’s response to a significant event in the short-term, by minimizing, re-defining it and focusing attention elsewhere (Glyshaw, Cohen & Towbes, 1989), research findings (E.g. Sigman & Wilson, 1998) associate avoidant coping styles with later psychological distress in adolescents (Sigman & Wilson, 1998).

Moving beyond coping styles, Sheehan and Draucker (2011) suggest that various elements of an adolescent's life may impact their level of adjustment to advanced parental illness. Particularly, they proffer the significance of inter-familial relationships to adolescent adjustment, and suggest that adolescents may experience greater distress, when family relationships are strained or conflictual. Moreover, results from their study, suggest that family relationships may continually change and transition following diagnosis, and these changes may hold important implications for adolescents. Furthermore, the study, in which nine parents with advanced cancer were interviewed alongside their ten adolescent children, and transcripts analysed using a constructionist grounded theory approach, suggests that time may also be an important factor for adolescents and their families. Particularly how they can best make use of the limited time they have together.

Overall, it appears as though adolescents may seek to adapt and cope with PI and bereavement in a number of different ways; demonstrating both adaptive and less adaptive coping styles (Herman-Stahl et al., 1995; Lawrence, 1996; Stemmler & Peterson, 1995). The significance of close and supportive relationships with parents, family and friends have also been highlighted. However, few studies explore adolescents' own perceptions and experiences of coping with a parent's prognosis, and little consideration appears to have been given to what they perceive as being helpful or unhelpful during this time.

3.3.4 Resilience and growth

Whilst adolescents may experience difficulties and struggle to cope and adjust following a parent's diagnosis (E.g. Grabiak et al., 2007; Ohannessian, 2007; Visser, et al., 2004), a small number of studies have also identified elements of resilience and growth stemming from adolescents' experiences of parental illness and death. For example, Phillips (2015) interviewed ten adolescents aged 14 to 17 years to gain further understanding of their experiences of advanced parental cancer. Upon analysing semi-structured interview transcripts using a hermeneutic phenomenological approach, results from the study suggest that despite the significant impact of advanced parental cancer on adolescents, it may also present an opportunity for growth and development. Factors such as family and peer support, open communication and a positive outlook are implicated, however the authors suggest that understanding how adolescents gain strength from family, peers and professionals is necessary to enhance service and intervention design.

Comparable findings were also reported by Jantzer et al. (2013), in their quantitative longitudinal study, exploring adolescents' experiences of parental illness. Results from the study suggest that despite challenges, adolescents were mainly able to adapt following a parent's cancer diagnosis (Jantzer et al., 2013). Seventy-four adolescents (11-21 years), who had a parent diagnosed with cancer, were interviewed, and findings suggest that adolescents may possess the necessary mechanisms required to adapt. Authors further pose the relevance and employment of "inner strength"; which they endorse as facilitative of positive adjustment. Kissil, Nino, Jacobs, Davey and Tubbs (2010) likewise explore the experience of young people coping with parental cancer. This qualitative focus group study similarly describes posttraumatic growth (PTG) experiences, in relation to African American adolescents faced with parental breast cancer. Results, following a content analysis, demonstrate four of the five domains of posttraumatic growth posed by Tedeschi and Calhoun (1996), including an enhanced appreciation of life and interpersonal relationships, increased sense of personal strength and changed priorities.

These studies demonstrate resilience and PTG in adolescents of unwell parents, however, not specifically parents with a terminal illness, and beyond these studies, the concepts of resilience and PTG are most commonly cited in relation to post-bereavement experiences. However, similar conclusions have been drawn and Lin, Sandler, Ayers, Wolchik and Leucken (2004) suggest that resilience may be determined by family and child variables, as was also reported by Philips (2015). The authors suggest that caregiver warmth, perceptions of less threat in response to negative events and personal efficacy in coping with stress may be significant. In another, more recent study, Brewer and Sparkes (2011) interviewed thirteen parentally bereaved young people (9-25 years), and similarly highlighted elements of PTG. Themes identified included, a positive outlook, gratitude, appreciation of life, living life to the full and altruism, and results again suggest that adverse life events can elicit positive change (Brewer & Sparkes, 2011). However, it should also be noted that the participants in this study experienced parental death at different points in time, with four participants being recently bereaved and the remaining participants being more than ten years post bereavement. Additionally, wide variations in nature of parental death are apparent; which may also have had bearing on findings.

Overall, whilst study findings seemingly demonstrate the relevance of concepts such as resilience and growth in relation to young people's experiences of parental illness and bereavement, few studies focus specifically on adolescents with parents in a terminal phase of illness. As such, it is not clear from the current literature and research whether these concepts are relevant and meaningful in this context.

3.4 Adolescents and support-seeking

3.4.1 The role of social support

In attempting to further understand why some adolescents may experience greater difficulties in response to parental illness and others may demonstrate a greater level of resilience or growth, it may be useful to consider adolescents' relationship with support and support-seeking. Results from Melcher et al. (2015) intimate the importance of adolescents being and feeling supported during periods of PTI, and parents are identified as a primary source of such support. However, friends, peers, teachers and professionals may also offer support for adolescents during this period, and a greater sense of social support has been associated with lower levels of depression (Gray, 1989). Yet, there may be particular barriers to adolescents gaining sufficient support. For example, Christ et al. (1994) suggest that adolescents would prefer to speak to someone who has a shared experience, however this may prove more difficult amongst adolescents, who typically have less experience with illness and bereavement than adults. Moreover, according to Thompson and Payne (2000) young people may feel different to their peers, and experience an increased level of teasing at school and McCarthy (2006) suggests that parental bereavement may create a perceived point of difference between adolescents and their peers; fostering a sense of isolation and stigma (McCarthy, 2006).

Results from Wong, Ratner, Gladstone, Davtyan and Koopman (2010), intimate that social support may be both a helpful and unhelpful factor for young people with an unwell parent. In their study, focusing on the perceived social support of children of cancer patients, twenty-nine participants (18-36 years) were interviewed; providing retrospective accounts regarding the impact of parental illness on their lives. Study inclusion criteria specified that parental diagnosis must have occurred whilst participants were aged between 8 and 17 years, and a grounded theory approach was employed. The analysis yielded five forms of perceived social support: Listening and understanding, encouragement and reassurance, tangible assistance, communication about illness and treatment and engaging in normal life experiences. Based on these findings, the authors contend that variations may exist in how young people perceive and experience social support, and subsequently, the individual nature of experience is intimated. However, the age range of participants included in the study was broad (8-17 years), and it could be argued that it is not unfathomable that significant differences were found in how social support was perceived and utilized by those at such different stages of development.

3.4.2 Service provision and interventions for young people and their families

In addition to family and social support, some adolescents may make use of more formal types of supportive services and interventions. Within the U.K. young people affected by bereavement may receive a wide range of psychosocial interventions; provided by public health and social services to hospices or private programmes (Rolls & Payne, 2003). Interventions include individual, group and family therapies, peer support and support groups (Webb, 1993) and offer more individualistic than manualised protocols frequently adopted in the U.S.A. (Christ, 2000; Cohen, Mannarino & Knudsen, 2004; Rolls, 2011). However, Rolls and Payne (2004) assert that children are not a homogenous group and understanding how young people can be best supported is a challenging undertaking. There is also a continued emphasis within clinical research on establishing the efficacy of interventions with young people experiencing different challenges at different developmental stages (American Psychological Association, 2006); specifically given the increased emphasis on outcomes in services receiving funding (Rolls, 2011). However, there are significant challenges associated with assessing the efficacy of interventions and Rolls (2011, p.3) states that, “the complex contextual nature of childhood bereavement makes it difficult to identify how interventions reduce or ameliorate the emotional, social and developmental experience of bereavement and its consequences over time, and what “clinical” outcomes (meaning attributable change available to direct observation) can be expected for a child who uses a service”.

Additionally, whilst some distinctions have been made between the type and efficacy of treatments required for children and adults; less frequently is a distinction made between the needs and experiences of children and adolescents (DoH, 2010). Wimpenny (2006) posits that the development of age-specific interventions may be required for adolescents, across a range of accessible settings, such as schools, health and social care settings. There also appears to be a much greater focus on the provision of support for the bereaved and there is an unclear picture of service provision for those preparing for bereavement. Moreover, only a few studies propose supportive interventions for when a parent is at the end of life. To illustrate this point, Philips’s (2014) systematic review of quantitative, qualitative and mixed methods publications between 2000 and 2013, found only four studies which proposed interventions suggested for adolescents of parents with advanced illness.

Of these studies, one was conducted by Adams-Greenly and Moynihan (1983), who posed preventative interventions aimed at preparing children to cope with the impending loss of a parent. The interventions outlined, included attempts to enhance parent’s ability to support their children and any psychological issues they may encounter, providing age-appropriate information, arranging hospital visits, assisting in bereavement preparation and providing follow-up contact.

Somewhat similarly, a more recent qualitative study, conducted by Bugge, et al. (2008) looked at children's experiences of how the Family Support Program (FSP) met their needs and supported their coping when a parent had incurable cancer. Participants (5-18 years) engaged in a family-based intervention approach, aimed at reducing risk factors and enhancing protective factors such as promoting understanding of the illness and its impact on the family. Results of the study indicate that the FSP increased knowledge, understanding and awareness, particularly in terms of the illness, the young person’s role within the family and knowing who they could approach for help. A further follow-up study conducted by the authors (Bugge, Helseth & Darbyshire, 2009), also explored parent’s experiences of the FSP, with positive findings. The parents expressed gaining greater insight into their children’s thoughts and responses to their illness and improved communication and reduced levels of conflict were reported.

In a further intervention study, Kennedy, McIntyre, Worth and Hogg (2008) explored perceptions of a new bereavement support service in Scotland for families impacted by PTI. Six families were recruited from a community palliative care service, and were asked to partake in individual and family group interviews. Analysis of pre- and post-intervention data were supported by QSR NVivo. Whilst findings intimate positive effects of the interventions, it is also suggested that those with complex and/or enduring needs may benefit most from targeted interventions, whereas many families may be adequately supported within the community and by drawing on personal support networks.

It could be argued, that only a limited amount of research has been conducted to present and validate interventions that may be of benefit to adolescents and families impacted by PTI, and it should be noted that whilst Philips’s (2014) review criteria posed that some method of analysis had to be used to evaluate outcomes of the interventions outlined, the four studies reviewed were largely descriptive and no quantitative form of analysis was used to assess intervention outcomes. Moreover, no comparison groups were used in the majority of the intervention studies outlined (Bugge et al., 2008; Bugge et al., 2009; Kennedy et al., 2008). Thus, whilst there is some evidence to suggest that specific interventions may be beneficial for adolescents and families impacted by PTI, further research is arguably required. Additionally, there appears to be a dearth of research exploring how adolescents perceive supportive services and how they may go about asking for and accessing additional support. Such research may hold significant value as Reardon et al. (2017) reports that only a minority of children and adolescents with mental health problems access treatment (Reardon et al., 2017), and Malone (2016) further contends that adolescents may be particularly reluctant to ask for help. Thus, it appears important to further understand adolescents' relationship with support-seeking, as even effective services and interventions are of limited value if adolescents do not access and engage with them.

3.5 Counselling psychology: working with bereavement, grief and adolescents

A further area of consideration in terms of the provision of support for young people in the U.K. is the professionals who work with this population. It has previously been cited that parents may experience difficulties in conversing with their adolescent children about TI and bereavement. However, there is also evidence to suggest that healthcare practitioners may themselves lack confidence in having and aiding conversations around death and dying. In Improving Supportive and Palliative Care for Adults with Cancer, the National Institute for Clinical Excellence (NICE, 2004) suggest that professionals may feel inadequately trained in such areas of communication and Fearnley (2010) similarly asserts that both training and ongoing professional development may fail to equip practitioners with confidence or competence to engage in conversations with the dying and their families.

A parallel could also be drawn here with the profession of counselling psychology, as working with issues relating to loss, grief and bereavement may form a large part of the work that counselling psychologists engage in, and on the BPS directory of chartered psychologists (BPS, 2017), all registered counselling psychologists detail working with grief and loss as within their remit. However, there is a limited focus within the professional doctoral training on the theoretical, empirical and clinical implications of grief related issues and counselling psychologists have contributed only a limited amount to the literature and research carried out in this area.

Moreover, the role of counselling psychologists working with children and adolescents is also a point of contention. Whilst the BPS counselling psychology training webpage states that "counselling psychologists work almost anywhere there are people" (BPS, 2013), there is no expectation of a trainee placement with children in counselling psychology training (Jones, 2011). This is notably different to clinical psychology training; where trainees typically undertake a core clinical placement with children and families. It may therefore seem unsurprising that applied psychologists working with children in the UK are mainly educational and clinical psychologists (Davy and Hutchinson, 2010) and there is limited literature regarding the work counselling psychologists engage in with children and adolescents (Davy & Hutchinson, 2010).

However, there may be an argument for counselling psychologists' suitability to working with adolescents, particularly when a parent is at the end of life; when considering the disciplines core values and principles. Firstly, Strawbridge and Woolfe (2010) pose that the profession of counselling psychology in the UK originates from humanistic philosophy and is underpinned by establishing and working within relationships with each individual. Based upon which, Sinitsky (2010) suggests that counselling psychology offers a unique contribution in facilitating the wellbeing of children and adolescents; through its emphasis on individual subjective experience. This may be of even greater significance within the field of bereavement and grief, where the experiences of adolescents have often been overlooked. As has previously been stated, existing theories and models of grief primarily focus on adult experiences and Davy and Hutchinson (2010) further intimate that interventions for young people are often based on the premises of adult-oriented therapies; as opposed to approaches designed for and researched in relation to young people and their families. Yet despite this common approach to working with young people, Malone (2016) poses that the assessment and treatment of adolescents confronted with loss, grief and trauma necessitates the use of approaches that differ to those used with children or adults. Given that counselling psychology places significant emphasis on "the subjective experience of clients and the need for helpers to engage with them as collaborators, seeking to understand their inner worlds and constructions of reality" (Woolfe et al., 2003, p.11), those within the profession may be well placed to advocate a holistic understanding of adolescents faced with PTI; within their developmental and wider social and cultural contexts. This may be achieved by counselling psychologists engaging in both research and clinical practice in this field, which is permissible given their role as "scientist-practitioners" (Woolfe et al., 2003, p.5).

As a second point, counselling psychologists may offer a non-medical model for working with adolescents; considering the discipline's deep-routed humanistic values, anti-psychiatry approach and focus on the therapeutic relationship (Strawbridge and Woolfe, 2010). This may be particularly salient in the current context, as despite difficulty and distress, only a relatively small number of adolescents report severe and enduring responses following parental loss (Rainville et al., 2012). Such findings, suggest that adolescent experiences of PTI and bereavement should not be approached from a pathological perspective (Folkner & Davey, 2002; Osborn, 2007; Rainville & Dumont, 2010). Rather, counselling psychology's approach to client-work may hold particular relevance; by perceiving difficulty and distress as part of the human condition, where there is also the potential for change and growth.

Thirdly, counselling psychology takes a prominent position in emphasizing the importance of early intervention (Sinitsky, 2010), particularly in facilitating processes of growth, change and development in young people (Davy and Hutchinson, 2010). Elements of positive change and growth have been highlighted in the literature, and Buchbinder, Longhofer and McCue (2009) argue that adopting a strength-based perspective, focusing on coping and adapting to changes brought about by PTI may help in preventing longer-term difficulties; as opposed to only responding to them. Similarly, Durlak, Weissberg and Pachan (2010) position that early and focused intervention can limit the extent and duration of symptoms and improve functioning, and such interventions may equip individuals with life skills and coping strategies (Cowen, 1985), which can be used in the context of present and future stressful life events (APA, 2014).

As a final point, there has previously been less investment in psychological services for children, and the provision of services for adults such as Improving Access to Psychological Therapies (IAPT) has been foremost (Davy & Hutchinson, 2010). However, the trajectory of literature and research demonstrates an increasing focus on children and adolescents and this is also reflected in service review and provision (Rolls & Payne, 2003; Rolls & Payne, 2004; Rolls & Payne, 2007). Indeed, IAPT was extended to include children in 2011 and an increasing number of government initiatives have since been aimed at improving children's wellbeing (Sinitsky, 2010). These elements of inclusiveness, individual subjective experience, early intervention, and promoting resilience and long-term wellbeing reflect the principles and values at the core of counselling psychology. Thus, whilst counselling psychologists may be "a relatively new breed of professional applied psychologists" (BPS, 2013), with less of a voice in this field, they may have much to offer.

3.6 Conclusions

Theories and models of grief form a central aspect of how loss is understood, and models such as the five stages of grief (Kubler-Ross, 1969) are taught and espoused amongst healthcare professionals (Bonanno, 2007) and have also entered into popular culture. However, it has been suggested that such prominent theories and models of grief, primarily centre on adult experiences, and less focus has been given to the nature of childhood bereavement and is trajectory (Rolls, 2011). Subsequently, popularized models are frequently borrowed and adapted for use with children and young people (Rolls & Payne, 2007). However, in doing so, it could be argued that there may be a failure to capture any distinct challenges or complexities associated with losing a loved one during childhood or adolescence (Balk & Corr, 2001) and consequently healthcare providers may be less attuned to young people's needs.

This may be of particular significance, as the death of a parent during childhood or adolescence has been documented as a stressful event (Lawrence et al., 2006; Marwitt & Carusa, 1998) which has been linked to depression, anxiety, hopelessness and suicidal ideation (Clements et al., 2004; Latham & Prigerson, 2004; Worden & Silverman, 1996). Moreover, there is evidence to suggest that PTI, which may precede bereavement, may be more challenging for young people than parental death (Saldinger et al., 2003; Siegel et al., 1996), and young people may be significantly impacted by parental illness in all areas of functioning (Visser, et al., 2004).

Adolescents have been highlighted in the literature and research as being the most susceptible to negative psychosocial outcomes when a parent is unwell (Grabiak et al., 2007), and it has been suggested that PTI may hinder normative developmental processes and lead to long-term psychological consequences (Ohannessian, 2007; Visser et al., 2004). Yet, only a small number of studies have considered adolescents' experiences of PTI (Philips, 2014), and those that have been conducted have included a wide age range of participants, despite older adolescence (15-18 years) being associated with the greatest levels of psychological distress (Birenbaum et al., 1999; Compas et al., 1996; Rainville et al., 2012; Welch et al., 1996). Moreover, few studies have focused exclusively on the terminal stage of illness; despite illness severity and reoccurrence being associated with adolescent adjustment (Grabiak et al., 2007).

There has also been limited consideration of how adolescents seek and make use of support during periods of PTI and following bereavement. Whilst supportive relationships with parents (Melcher et al., 2015) and peers (Gray, 1989; Wong et al., 2010) have been highlighted as significant in adolescent adjustment to parental illness, inconsistent findings are also apparent (Wong et al., 2010), and few studies have considered adolescents' experiences of and need for support from their own perspective. Adolescents' experiences and perceptions of support may be of particular significance, as they have been identified as a group who are less likely to access treatment (Reardon et al., 2017).

Bremner (2000) has suggested that when experiencing grief, adolescents might be a particularly vulnerable group, however, the potentially complex nature of their relationships with adults and their reluctance to acknowledge dependency on them may make adolescents a challenging group to help. Adding to these challenges, adolescents less inclined to access services, who may be utilizing avoiding coping strategies may also be more likely to evade participation in research (Lawrence et al., 2006). Thus, there are current challenges in understanding the needs of this group, engaging those in need and providing appropriate support.

Whilst the role of counselling psychologists working with children and adolescents is less prominent than other applied disciplines such as educational and clinical psychologists (Davy and Hutchinson, 2010), the discipline may have much to offer; particularly in terms of its core principles and values. Individual subjective experience is central to counselling psychology (Woolfe et al., 2003), and may lend to eliciting the lesser-heard narratives of adolescents facing bereavement. Moreover, the discipline's emphasis on "facilitating growth and the actualisation of potential" (Cooper, 2009, p.120) may be particularly relevant in working with adolescents on the cusp of adulthood; who alongside adverse circumstance such as PTI and bereavement, confront developmental challenges and choices, which may irrevocably affect their future. Furthermore, one of the most significant challenges in working with adolescents, may be engaging them (Bremner, 2000), and therefore counselling psychologists continued focus on building and maintaining a strong therapeutic relationship with clients (Strawbridge & Woolfe, 2010) may further lend to work with this group.

In light of the reviewed literature and research, this study aims to investigate retrospectively how older adolescents (16-18 years) may experience and respond to PTI, with consideration to how they may perceive or experience support during this period. As such, this study aims to provide clinically relevant information for healthcare professionals working with bereaved adolescents or those presently experiencing PTI; including recommendations around family and peer support and service provision and intervention, which may be of use to adolescents during this period.

3.7 Research questions

Based on the reviewed literature and research this study seeks to address the following research questions:

- How do 16-18-year-old adolescents experience and respond to PTI and bereavement?
- What are their perceptions and experiences of support during this period?

4.0 Method

4.1 Overview

The objective of this research is to understand how individuals describe and make sense of their experiences of parental terminal illness during adolescence. It aims to explore experiences of personal, familial and wider social and psychological adjustment and individual perceptions of available support using a qualitative research methodology. This research utilises semi-structured interviewing and Interpretative Phenomenological Analysis (IPA). This chapter will firstly provide a rationale for the chosen methodology, followed by a description of the strategy employed. Subsequently, a description of the recruitment, data collection and analysis procedures will be provided.

4.2 Rationale for Qualitative Methodology

The literature review found that there is currently limited empirical research focusing on PTI during adolescence. Similarly, a lack of research-based theories and models relating specifically to young people's bereavement experiences is noted. With this in mind, Rizq and Target (2008) suggest the usefulness of qualitative research "where the field of interest is characterised by complexity, ambiguity and lack of prior theory and research" (p.67). Moreover, Willig (2008) suggests that qualitative research seeks to capture the quality and texture of experience. As such, a qualitative approach was considered particularly appropriate in addressing the aims and objectives of the current study, as it provides an exploratory method of investigation; allowing for exploration of how adolescents may experience and respond to PTI and bereavement, and how they may perceive and experience support.

Qualitative research tends to focus on meaning, particularly how people understand and make sense of the world and give meaning to their experiences (Willig, 2008). As such, qualitative researchers aim to bring understanding to what it may be like to live through particular events or situations. This was particularly relevant to the aims and objectives of the current study, which sought to bring further understanding to what it may be like to live through PTI and bereavement during adolescence.

Whilst quantitative research may attempt to predict outcomes, qualitative research lends to a focus on processes, such as how individuals experience a particular phenomenon "in its full richness and in its greatest depth" (Van Manen, 1990, p.20). Quantitative research methods allow the researcher to quantify or measure the phenomenon of interest in order that they may make predictions or wider claims (Langdridge and Hagger-Johnson, 2009). In contrast, qualitative research methods aim to elicit rich descriptive accounts, which are not intended to be broadly generalizable. Rather, an emphasis is placed on individual subjective experience and the construction of individual and shared meaning. This was compatible with the aims of the current study, in terms of seeking to elicit rich descriptive accounts of experiences of PTI and bereavement.

Qualitative researchers tend not to focus on cause-effect relationships or variables defined by the researcher (Willig, 2008). They are rather concerned with the meanings ascribed by the participants themselves, in their own words. As only a limited amount of research has been conducted in this area, this study sought to bring greater understanding to the experiences of PTI and bereavement during adolescence; with a particular focus on how individuals describe and make sense of their experiences, in their own words.

It is also noted that there is a particular lack of qualitative research that has been conducted in this area. As such, questions remain to be answered about how adolescents experience PTI, and what particular challenges they may encounter. Thus, a qualitative approach appeared to be particularly appropriate, in aiming to understand the nature and complexity of the beliefs individuals have about their personal and social worlds (Smith, 1995). Moreover, qualitative methods provide an inductive approach to research, in seeking to capture the complexity of individual experience (Rizq & Target, 2008), and allowing for new or unanticipated insights to emerge.

Furthermore, the aims and objectives of the current research align with the focus of qualitative research on prizing the uniqueness of individual experience and attempting to further understanding of a particular phenomenon through meaning and description (Berg & Lune, 2014). As such, a qualitative research methodology was deemed most suitable for the present study in facilitating the capture of rich narrative accounts of PTI during adolescence and individual perceptions and experiences of support.

4.3 Overview of Methodology and Method

Phenomenology is a qualitative research approach, derived from the twentieth century philosophical positions of Edmund Husserl and Martin Heidegger (Reiners, 2012). Husserl expressed that phenomenology, suspended all assumptions, it was related to consciousness and based on the meaning of an individual’s experience. Consequently, Husserl’s descriptive phenomenological approach asserted that individual experiences could be described whilst preconceived ideas were set aside or bracketed (Reiners, 2012). Conversely Heidegger asserted that the researcher’s experiences relating to the matter of study could not be evaded and instead the relationship between researcher and researched was inherent to the phenomenological approach. He therefore developed interpretative phenomenology through extending hermeneutics; which focuses on the concept of being within the world rather than knowing the world (Reiners, 2012). Heidegger's approach moves beyond description of experience and aims to expose meanings attributed to experiences (Lopez & Willis, 2004). As such, these phenomenological researchers generally aim for novel, rich, complex descriptions of a phenomenon as it is lived (Finlay, 2009).

Interpretative Phenomenological Analysis (IPA) as outlined by Smith, Flowers and Larkin (2009) stems from the hermeneutic tradition to create an idiographic and inductive approach, which aims to explore individual's personal lived experiences, with due focus on the individual's perceptions or sense-making process. (Finlay, 2009). The *hermeneutic* underpinning in IPA is reflected in the researcher's engagement in the understanding and interpreting of the participant's experiences (Smith et al., 2009). As the researcher cannot directly access the participants' experiences, they must try to make sense of the participants' experiences, whilst the participant is trying to make sense of their own experiences, creating a double hermeneutic (Smith & Osborn, 2008). IPA also adopts an idiographic stance, in that the particularities and complexities of individual cases are explored and interpreted before a "cautious engagement" (Willig, 2008, p.88) with wider cases and theory. The strong idiographic, narrative element of IPA, distinguishes it from other phenomenological approaches and asserts the significance of individual experience; as illustrated by the analytic process whereby participant interviews are analysed in depth individually and participant quotations are used to ensure that interpretation remains connected to the individual participant transcript. The underpinnings of IPA lend themselves to the current research, where insight into the lived experiences of adolescents with a terminally ill parent are sought as well as an understanding of how they make sense of their personal and social world (Smith, 2008).

4.4 Rationale for IPA and Alternatives Discounted

IPA was chosen as the preferred qualitative method for a number of reasons. Firstly, its aim of conducting a detailed exploration to capture individuals' lived experiences (Smith & Osborn, 2003) is in line with the aim of the current research. Secondly, IPA places emphasis on how study of the particular can lead towards the more universal; as the experiences, perceptions and understanding of a small group may offer relevance in a wider context (Smith, 1996; Smith et al., 2009). In addition, IPA's emphasis on how individuals make sense and reflect upon their experiences fits with the intention of this study (Breakwell, Hammond, Fife-Schaw and Smith, 2006). Smith et al. (2009) expand that "when people are engaged with 'an experience' of something major in their lives, they begin to reflect on the significance of what is happening and IPA research aims to engage with these reflections" (Smith et al., 2009, p.3).

The application of IPA within psychology research pertaining to health and ill health can also be noted. Brocki and Wearden (2006) suggest that this is because IPA offers researchers an opportunity to learn about people's lives and experiences and is particularly useful when eliciting illness narratives; as it allows the participant more space and freedom to tell their story. IPA also allows for the exploration of change over time which is particularly pertinent to the shifts and fluctuations of health and ill health (Brocki and Wearden, 2006) and bears particular relevance to the current study. Additionally, IPA is inductive in nature and thus lends to exploring the complexity of human experience. It is not solely concerned with existing knowledge, and as such allows unanticipated themes to emerge. This similarly aligns with counselling psychology's ideographic and subjective approach to clinical practice and research.

Furthermore, IPA was deemed more suitable than other qualitative approaches for the purposes of this research. For instance, other Phenomenological methods, such as Descriptive Phenomenology. Descriptive phenomenology acknowledges the role of interpretation when analysing perceptions and experiences, yet it is asserted that interpretation can be minimised by the researcher bracketing off their past knowledge and experience of the phenomenon being explored (Willig, 2008). IPA rather draws on hermeneutic tradition; positioning that all description is some form of interpretation. IPA therefore places less emphasis on attempting to bracket presuppositions and assumptions but rather poses that understanding cannot occur without preliminary knowledge or assumptions of a phenomenon. IPA was also favoured over Grounded Theory (GT), which was developed "to generate or discover a theory, an abstract analytical schema of a phenomenon that relates to a particular situation" (Creswell, 1998, p.56) whereby the researcher adopts a bottom-up approach to create a nexus between theory and its grounding data. The current study was not concerned with developing new theories or the macro-level exploration of trends facilitated by GT. Rather the micro-analysis of individuals' experiences, emphasised by IPA was more compatible with the aims of the current study (Smith et al., 2009). Currently, limited empirical research has been conducted in this area specifically focusing on adolescents and the terminal phase of a parent's illness and Smith and Osborn (2004) suggest that IPA is a favourable approach to research if the area of study is under-researched or new. Thus, IPA provides an opportunity to conduct an exploratory study in order to obtain rich details concerning the general experiences of participants rather than a conceptual focus with the aim of developing a theory or a model of process, as with GT.

As such, the emphasis of the current research on the participants' understanding of their own experience of parental terminal illness and the exploration of their perceptions of support, suggests that the research question is suited to IPA rather than other approaches such as descriptive phenomenology or GT.

4.5 Ontology and Epistemology

The choice of methodology was also considered in terms of ontology and epistemology. Ontology is concerned with the nature of being, "to what exists in the world, to the nature of reality" (Punch, 1998, p.170). The current study's ontological position is one of constructivism; whereby a set 'truth' or 'reality' cannot be "known" or "discovered" in a subjective world (Pring, 2004). Rather 'reality' is constructed from individual perceptions, and as such cannot be considered as absolute (Bryman, 2001). A constructionist approach to research therefore aims to explore patterns and meanings (Madill, Jordan & Shirley, 2000) co-constructed between individual's reactions in the world; as influenced by personal, historical and socio-cultural contexts (Madill et al., 2000; Gergen, 2001). The ontological position of the current study aligns with the idiographic nature of phenomenology. Equally, it is compatible with the emphasis of counselling psychology on the social construction of identity and experience (Woolfe, Strawbridge, Douglas and Dryden, 2010).

The current study adopts an interpretative and relativist approach whereby the research is viewed as inductive and reality as subjective (Blaikie, 1993). An emphasis is thus placed on the construction of reality, as negotiated by both researcher and participant subjectivities. In keeping with the epistemological positioning of the current study, Interpretative Phenomenological Analysis (IPA) creates an idiographic and inductive approach, which aims to explore individual's personal lived experiences, with due focus on the individual's perceptions or sense-making process. (Finlay, 2009).

4.6 Procedures

4.6.1 Research design

Semi-structured interviews were conducted with six participants. These interviews were audio-recorded, transcribed and analysed using IPA (Smith and Osborn 2008).

4.6.2 Sampling and participants

Smith et al. (2009) recommend a sample size of between four and ten participants for conducting professional doctorate research. Due to the research question this study sought to address, and the personal and sensitive nature of the topic, it was determined that six interviews would allow for a sufficient examination of divergence and convergence within the sample (Brocki & Wearden, 2006), whilst also prizing sufficient richness and depth (Van Manen, 1990; O'Reilly & Parker, 2014). In line with the theoretical underpinnings of IPA, participants were selected purposively on the basis of having experience of parental terminal illness during adolescence. To address the purpose of the study and to ensure homogeneity of the sample, the following inclusion and exclusion criteria was adhered to: Participants were required to have had a parent who received a formal diagnosis of a terminal illness whilst aged 16 to 18 years. Only adults (i.e. over 18 years of age) were included in the study to avoid any ethical age-related issues. Finally, anyone who may have recently been diagnosed with a mental health condition such as anxiety or depression would have been thanked for their interest but asked not to participate in the study; due to a potentially increased likelihood of participant distress. Details of the inclusion and exclusion criteria were also detailed in the information sheet (Appendix E).

Participants were six individuals, five female and one male, all of whom were Caucasian British and spoke fluent English as their primary language. The participant demographics have been outlined in table 1.0 for assessment and to contextualise the research findings. Careful consideration was given to ensure that any potentially identifying information was not included in this table, to uphold confidentiality and anonymity.

Table 1.0 Demographic information for the six participants

Nationality	N	Gender	N	Parent Diagnosed	N	Current Age	N	Age at TD	N	Geographical Location	N
British	6	Male	1	Father	3	24-25	3	16	2	North East	2
		Female	5	Mother	3	26-27	1	17	1	North West	3
						28-29	2	18	3	South West	1

* Age at TD = Participant's Age at time of Parent's Terminal Diagnosis - N = Number of Participants

4.6.3 Recruitment procedures

Participants were recruited by posting a recruitment advertisement on internet groups and forums and social networking sites; a list of which is located in the appendices (Appendix B). Three responses were received through the social networking site Facebook. Of these responses, all matched the inclusion criteria. A further four participants registered interest stemming from snowball sampling (Vogt, 1999). One was filtered out due to not reaching the criteria of being aged 16 to 18 years at the time of parental terminal illness diagnosis.

Contact was made with potential participants via telephone, at which point confidentiality was discussed. Information was provided regarding the study and participants were asked basic questions to ensure they met the inclusion criteria; any participant questions were also answered. Permission was subsequently granted to send the study information pack via post. The pack included; a further copy of the recruitment poster (Appendix D), a detailed information sheet (Appendix E), a consent form (Appendix G) and stamped return envelope. Upon receiving the completed consent forms, participants were contacted to arrange interview.

4.6.4 Materials

The materials used throughout the research process are listed below and have been included in the Appendices section of this thesis:

- Interview Schedule (Appendix K)
- Recruitment poster (Appendix D)
- Participant information sheet (Appendix E)
- Participant consent form (Appendix G)
- Distress Protocol (Appendix H)
- Debriefing sheet (Appendix I)
- Sources of additional support sheet (Appendix J)

4.6.5 Ethical considerations and procedures

Ethical clearance for the study was granted by London Metropolitan University Ethics Committee (see Appendix F) prior to recruitment. The British Psychological Society's Code of Ethics and Conduct (2009) and Code of Human Research Ethics (2010) were reviewed and considered during the design and execution of this study.

Prior to each interview the participant was provided with information about the study, including the purpose of the study, information regarding how the data would be handled and confidentiality. Participants were informed that they had the right to withdraw from the study at any time prior or during the interview and up to four weeks post interview, without giving a reason. An official university contact was also provided should the participant wish to raise any queries or concerns. After this information was provided, participants were asked to sign a consent form (Appendix G).

Participants' names and potentially identifying information was not included in the study write-up. Identifying information was stored separately from audio-recordings and transcriptions. All research materials and information was also kept password protected. Participants were made aware that audio recordings would only be kept until the doctoral qualification had been conferred, at which time they would be destroyed. Anonymised data would however be kept for a period of ten years post submission, in line with London Metropolitan University Thesis Guidelines. Participants were informed that they were not obliged to answer the interview questions and the interview could be terminated at any time. As participants were asked to talk about emotive and potentially upsetting experiences during the interview, a distress protocol (see Appendix H) was adhered to, to minimise risk and ensure participant well-being. At the end of the interview, participants were provided verbally with debriefing information. This included both researcher and supervisor contact details and sources of additional support. Participants were informed that a debriefing sheet (see Appendix I) and a contact sheet for support services (Appendix J) would be also posted to them the same day.

4.7 Data Collection

4.7.1 Interview schedule

A semi-structured interview schedule was developed (See Appendix K) by designing open-ended questions in-keeping with the research aims and objectives and in line with guidance on interview schedule development (Smith & Osborn, 2008; Smith et al, 2009). The interview questions were formed based on relevant literature and developed through discussions with IPA-experienced research supervisors, and through group discussion. The questions were designed to be open-ended, and the schedule was used flexibly to facilitate exploration of additional areas of insight and to encourage the collection of open and rich accounts (Smith & Eatough, 2006). A pilot interview was conducted within a peer-led IPA group to ensure that the schedule was adequate in addressing the aims of the study (Smith & Osborn, 2008). Following this role-play pilot interview and collaborative discussion within the peer group, minor modifications were made to the interview schedule, namely the incorporation of additional prompting questions; which aimed to encourage a deeper level of exploration.

4.7.2 Interview procedure

Telephone interviews have been used less frequently than face-to-face interviews in qualitative research (Opdenakker, 2006; Sweet, 2002), however they may offer a useful and adaptable method of data collection (Carr & Worth, 2001). Researchers that have employed telephone interviews have described participants as being relaxed on the telephone, and able and willing to talk openly and disclose sensitive information. Moreover data collected via telephone interview has been depicted as of high quality; being particularly rich, vivid and detailed (Chapple, 1999; Kavanaugh & Ayres, 1998; Sturges & Hanrahan, 2004).

However, several limitations of telephone interviews have been referenced, most particularly the absence of visual cues (Garbett & McCormack, 2001). These lost visual cues cannot be analysed and furthermore, the absence of visual cues may in some instances hinder the researcher's ability to respond effectively to the participant. It has also been contended that there may be a greater potential for participants to become distracted in their environment in the instance of telephone interviews (McCoyd & Kerson, 2006; Opdenakker, 2006), however this has also been reported in face-to-face interviews (Sturges & Hanrahan, 2004).

These concerns have been somewhat addressed in the literature, and it has been suggested that visual cues may not actually be used extensively in analyses, and there may be ways of compensating for their absence; such as an awareness of tone (Opdenakker, 2006), pauses and sighs (Sturges & Hanrahan). Furthermore, there may be specific advantages to utilizing telephone interviews, such as: greater access to participants across wider geographical areas (Sturges & Hanrahan, 2004; Sweet, 2002), increased safety of the interviewer (Carr & Worth, 2001), the ability to take discreet notes (Carr & Worth; Smith, 2005) as well as facilitating a greater level of anonymity (Sweet, 2002; Tausig & Freeman, 1988), less social pressure and increased rapport (McCoyd & Kerson, 2006).

These strengths and limitations of telephone interviews were extensively considered, however the researcher was particularly persuaded by findings suggesting the usefulness of telephone interviews for collecting rich narrative data on sensitive topics (Drabble et al., 2016). It has been reported that participants may be able to discuss sensitive information more openly when the interviewer is not present (Hopper, 1992), and Mealer and Jones (2014) argue that qualitative telephone interviews can limit potential emotional upset due to the comfort associated with virtual communication. Furthermore, Drabble et al. (2016) and Trier-Bieniek (2012) argue that telephone interviews may be preferable when talking about personal and painful experiences as participants are "being interviewed in familiar, comfortable settings and can dictate the course and direction of the interview" (Trier-Bieniek, 2012, p. 642). It was therefore felt that telephone interviews may be particularly useful given the aims and objectives of the current research; in terms of eliciting rich descriptive accounts of how individuals may experience and respond to PTI and death during adolescence.

In light of the decision to undertake interviews via telephone consideration was given to the potential ethical implications. In particular, the researcher was acutely attuned to any signs of participant distress and a distress protocol was constructed based on the recommendations of Draucker, Martsolf and Poole (2009) on the development of distress protocols for research concerning sensitive subjects. Participants were also provided with a contact sheet for sources of additional support. It was also asked that any potential participants recently diagnosed with a mental health condition such as anxiety or depression did not participate. For all participants a significant amount of time had passed since their parent's death and it was therefore felt that severe distress was unlikely to occur. However, it was included in the distress protocol, as with all points to enable the researcher to identify, and minimise any potential distress or anxiety experienced by a participant as a result of the research process.

All of the interviews were conducted via telephone on a date and time to suit the participant. Interviews were carried out over 40 to 60 minutes and the hand-held digital recording equipment was introduced to the participant, before being switched on. The interview schedule was comprised of six main questions focusing on personal experiences of parental illness, family relationships and dynamics and coping and support. Additional prompts were used depending on the responses given (Smith and Osborn, 2008). However, the interview was designed to be conversational to allow for open and free discussion.

4.8 Data Analysis

The interview recordings were transcribed in their entirety, ensuring that all audible elements were included; such as pausing, sighing, laughing and emphasis (Smith and Osborn, 2008). All potentially identifying information was omitted or altered to protect the anonymity of participants. Participant names were changed to numbers, relating to the chronological order in which the interviews took place (1 through to 6). The transcriptions were formatted in line with IPA guidance (Smith et al., 2009); including margins on either side of the transcriptions for note writing and page and line numbers were added (see example of transcript layout in Appendix M).

The analytic process was informed by Smith et al. (2009) which facilitates a movement from the individual to the shared and from the descriptive to the interpretive (Smith & Osbourne, 2003) through the following stages. Initially the transcripts were read for meaning. This involved reading a singular transcript several times independent of the others; to enhance engagement with the text and to insofar as possible step into the participants shoes (Breakwell et al., 2006). Subsequently, initial noting began by annotating the right hand margin with initial ideas, thoughts, and anything that appeared interesting or significant (Smith et al., 2009). Attention was paid to linguistic, descriptive and conceptual features and any initial associations or contradictions were detailed. Initial ideas noted in the right hand margins were then condensed into more interpretative categories where deductions were made regarding what sense the participant was making of their experience; staying close to the text so as to ensure interpretations remained grounded in the participants words (Breakwell et al., 2006).

These interpretative categories were then transformed into “emergent themes”. The emergent themes served to draw out patterns of meaning from the transcript; with a focus on what was felt about what the participant was saying. These were displayed in the left hand margin. At this point the emergent themes were studied and colour coded to enable their clustering with related themes. Initial themes which were not strongly evidenced were at this point discontinued, and the remaining themes were labelled to represent their meaning. These were then displayed in a theme table (see Appendix O) which includes illustrating quotations from the transcript (Smith et al., 2009). This process involved continually moving between the themes and the transcript to stay as closely linked as possible and to avoid missing important information. These stages of the analytic process were then completed for each transcript. As IPA is acutely “idiographic” each transcript was examined independently, allowing each case to be analysed in its own terms. It was thus important to bracket ideas emerging from previous transcripts to prevent reading for similarities, which may otherwise occur (Smith et al., 2009).

The final stage of analysis involved the comparison and integration of themes for all participants. This involved focussing on the commonalities and differences which could be identified throughout the transcripts in order to define higher order or superordinate themes and sub themes which could be evidenced using quotations. Using quotations assisted in keeping interpretations grounded in the participants’ words. Furthermore, superordinate themes were then checked against the transcripts to ensure that the richness of each account had not been lost through the integration of themes. It was felt that the final superordinate themes were significant to all six participants.

4.9 Quality Procedures

4.9.1 Reliability and validity

The quality and validity guidelines put forward by Yardley (2000) were referred to throughout this study and the four broad standards of: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance were used as guiding principles. Throughout interviews, attempts were made to clarify what the participant was saying and check the researcher’s understanding to ensure that their voices were accurately represented. Furthermore, the researcher sought to explore and incorporate multiple perspectives through the use of supervision and peer review. This was useful in developing and substantiating ideas and themes (Breitmayer, Ayres & knafl, 2007). Also from a social constructionist perspective, as realities are perceived as being co-constructed, the integration of multiple perspectives may be seen to lead to a deeper and richer understanding of a phenomenon (Smith, 1996).

A reflective diary was also kept throughout the research process (Smith, 1996) in which initial ideas, assumptions, biases, interests, concerns, influences, discussions and personal and professional development points were explored (see Appendix L). The reflective diary also formed part of supervision discussion to aid open exploration of ideas and reflexivity.

5.0 Analysis

Table 2.0 Master Theme Table

Superordinate Themes	Subordinate Themes	Transcript/ Pg/Line	Keywords
Changing family dynamics	Changed beyond recognition	6.19.299-300	She couldn’t do anything
		1.10.153-154	He wasn’t really himself
		2.19.310-311	It wasn’t him you know
		5.26.434-435	She wasn’t the best anymore
	Strengthened relationships with surviving parent	1.29.493	My mum and I got a lot closer
		6.32.512	My dad is literally like my rock
		4.21.334-335	We’ve never been as strong
	New roles and responsibilities	2.25.421-422	We became more like on a level
		5.26.434-435	It was an inverted childhood
		1.25.427-428	Trapped between being an adult and a child
		5.35.609	It meant taking care of mum
		6.14.205-210	Your family needs you
		4.17.275-276	He struggled to be able to know what to do
	Protecting each other	1.12.189-190	They’re trying to protect you
		2.21.350	He was probably just trying to protect us
		3.26.443-444	I didn’t want to upset her
Grappling with adolescence and adjustment to loss	Struggling/not wanting to understand	3.8.109-110	I just never ever thought it was going to be something like that
		4.5.56-57	I didn’t know what a hospice was
		5.5.60-61	I didn’t really know what the word meant
		3.12.189-190	I just refused to see it as a serious thing
	Finding a means of coping	6.15.228-229	You sit and you get on with it
		1.10.159-160	Be strong and try and carry on as normal
		2.24.399-400	We just pretended things were normal
		4.23.371-372	I sort of went off the rails
		5.28.470-471	Mainly getting drunk…or smoking weed
	“It was kind of an awkward difficult phase”	1.43.735-748	There’s that much going on
		6.10.153-154	I’m meant to be going to a music festival
		1.8.115-118	I was learning to drive…I was doing my A Levels
Barriers to feeling supported	“No-one my age really knows what to do”	1.18.302-303	It became very divisive amongst me and my friends
		2.26.430-431	I never really spoke to them about how I felt
		4.34.538-539	They say “oh yea, I understand it” but they don’t
	Stereotypes and stigma	1.20.326-327	The one who has the dead parent
		1.6.84-85	Counselling is a funny word
		5.29.498-499	It’s not right for a man to cry
	[Counselling] “It’s a good concept”	4.30.472-473	It took absolutely ages for me to get the appointment
		1.42.724-725	They think of smaller children
		1.8.120-126	I was expecting her to give me answers
		5.31.532-533	They wanted to have basically cured you
		4.31.495-496	I wanted to do it my way
Living with the consequences	Guilt and regret	1.26.441-442	A lot of things that weren’t said
		4.6.90-91	I think I had a lot of guilt
		3.24.409	I just really really ashamed
		5.21.348	Incredibly shameful, guilty thing
	New sense of mortality	1.38.652-654	I do worry about people getting sick
		2.37.623-625	I’m like a nervous wreck
		3.30.513-515	I would immediately think the worst
	Impact on education and life direction	2.7.97	You were thinking about obviously going to uni
		1.17.282	My teacher became quite accepting
		5.46.806-807	I was given just enough rope to hang myself with
		5.44.767-769	I do want to make a difference
		4.42.688-689	We’re all in the caring profession
	The ongoing process of loss	1.21.340-341	I would have loved him to meet my boyfriend
		4.16.246-247	We started to get close again
		5.25.431-432	I’ve never loved anyone as much as I loved her

In this analysis section each superordinate theme (as detailed in table 2.0) will be presented in turn, using supporting extracts from participant transcripts.

5.1 Super-ordinate theme: Changing family dynamics

Participants related how, as a consequence of their parent's illness, their family structure and life significantly changed. Relationships with both parents were depicted as being transformed. A renegotiation of roles and responsibilities was also presented. As was a change in family communication patterns, particularly in navigating difficult and upsetting information. As adolescents, these elements proved distinctly challenging. The participants had greater awareness of and exposure to their parent's illness than younger siblings. They were also increasingly depended on. Thus, a struggle is presented in attempting to adjust to premature levels of responsibility, and more broadly in attempting to adjust to their family being irrevocably altered.

5.1.1 Changed beyond recognition

Participants remarked upon how their parent significantly changed during the course of their illness and this was highlighted in terms of physical deterioration and also changes in temperament and personality. Witnessing a parent's worsening condition created confusion, anxiety and distress for the participants who depict their parents as being changed beyond recognition.

Participant 1 and 6 express the emotional and psychological impact of these changes.

> Participant 6: "That was it. Like she couldn't move, she couldn't speak, she couldn't do anything." (6.19.299-300)
>
> Participant 1: "He wasn't really himself at the end. He'd, he'd completely wasted away to a skeleton […] erm because of his liver problems he was yellow, he didn't have any control over his bodily functions, he couldn't speak, he couldn't really see properly […] but […] it was all very […] traumatic to be there and to see him like that" (1.10.153-154)

Throughout her interview participant 6 reflects on the losses brought about by her mother's illness; from the loss of her hair to a more profound loss of autonomy and independence. Each loss is presented as something to grieve but also something to adjust to. However, at this point her description of loss becomes less graded. "That was it" appears to mark an ending, and it may be that she identifies this as the time she lost her mother albeit before her death. Participant 1's statement that "he wasn't really himself" similarly reflects a sense of her father being lost. The description of his condition demonstrates how distressing it was for her to witness and it may be that presenting her father as not being "himself" helps her to cope.

For participant 2, the changes in her father's disposition were particularly distressing.

> Participant 2: "Oh I feel horrible saying this […] but it wasn't him you know, it wasn't him at all. He was nothing like that, his whole mood changed and he was just, not really interested in much." (2.19.310-311)

It was extremely difficult for her to talk about this element of her father's illness and she appeared to feel guilty and fearful of presenting him in a negative light. Participant 2 repeated how "it wasn't him" and "he was nothing like that". This serves to separate her father from his illness and to make it clear that these were changes brought about by the illness. In doing so, participant 2 may be attempting to protect herself and her father's memory from the upsetting circumstances preceding his death.

Participant 5 equally strives to separate his mother from her illness.

> Participant 5: "the Cancer took hold of her, the tumour ripped out her memory and her wit, um, and her [….], uh, erudite touch, like she wasn't the best anymore." (5.26.434-435)

He personifies her illness, describing how it "took hold" of his mother and "ripped out" parts of her. Earlier in his interview Participant 5 had affectionately described his mother as "an exceedingly, extraordinarily happy and energetic character" and shared detailed anecdotes to illustrate her personality. These serve as a distinct contrast as he describes the progression of his mother's illness, until "she wasn't the best anymore". He appears sad through his language and tone, and similar to the other participants, there is a sense of his mother being lost prior to her death.

The physical and dispositional changes caused by illness alter the participants' relationship with their parent. The illness appears to have stopped the parent being a source of comfort and security. Rather, the evident changes are distressing and frightening. It appears as though the participants sought to separate their parent from their illness as a way of making sense of upsetting physical and dispositional changes. Stating "it wasn't him" or personifying the illness "the cancer took hold of her", creates a distinction between who their parent was and who their illness made them. There is subsequently a sense of the parent being lost and grieved for prior to bereavement.

5.1.2 Strengthened relationships with surviving parent

Most participants spoke about how their relationship evolved with their surviving parent. They referred to finding new ways of relating to each other and establishing a deeper connection. Participant 1 reflects on her relationship with her mother.

> Participant 1: "Erm […] my mum and I got a lot closer definitely. Erm […] but I think we kind of both tried to deal with it in a similar way […]" (1.29.493)

She definitively describes becoming closer to her mother following her father's terminal diagnosis and attributes this somewhat to their similarities in dealing with the prognosis. Several participants reported finding it difficult to relate to others their age during their parent's illness and following their death, and so centred on their family for support; particularly the surviving parent.

> Participant 6: "my dad is literally my rock. If anything happened to my dad I literally don't know what I would do." (6.32.512)

Participant 6 presents her father as a sturdy and unmoving rock, showing the invariable support and consistency he provides. Her fear of losing him is apparent, and several participants echoed such a fear. It may be that losing a parent has created a greater parental appreciation, leading to an enhanced bond with the surviving parent. Alternatively, the loss of a parent may be seen as creating a more insecure attachment to the surviving parent, as the adolescent fears being separated from them too; if they were to become ill and die.

Most participants described an enhanced relationship with their surviving parent. However for some, this transformative process was gradual and ongoing.

> Participant 4: "um […] me and dad, um, we […] we get on with each other, um, a lot more now. We actually have conversations with, with each other. He's trying to make amends big style." (4.21.334-335)

> Participant 4: "Um he's being, he's being a dad. So it's […] I think that point, obviously, we still have a lot of ups and downs but we all come together now and […] we've never been as strong to be honest." (4.21.334-335)

For participant 4, being able to communicate more effectively with her father is prized. Her expression of "we actually have conversations" alludes to an uncommunicative and unconnected prior relationship which has and continues to evolve. Her reference to "making amends" and "he's being a dad" implies an earlier dissatisfaction with him fulfilling his role as a father. Equally, a gradual family healing process is alluded to.

Participant 4 alongside the other participants within this theme, seemingly demonstrate elements of growth; insofar as pain and struggle have fostered strength and positive change.

5.1.3 New roles and responsibilities

Participants shared similar experiences of adopting new roles and responsibilities within their family following their parent’s diagnosis. As older adolescents, they were more mature than younger siblings and able to help out where younger family members could not. The increasing demands placed on the family by the illness seemingly led the adolescents to be increasingly relied upon.

> Participant 2: “I just tried to be a little bit more […] mature about things and I just tried to help out more with the baby […] I don’t know, I just tried […] I think our relationship changed in the way we worked together. We became more like on a level than you know, mother-daughter […]” (2.25.421-422)

Participant 2 takes on a greater level of responsibility within her family. Helping her parents to look after her younger siblings creates a levelling of roles; seemingly propelling her into adulthood. This is supported when she describes her relationship with her mother as less “mother-daughter” and more “on a level”. Yet, within her repetition of “I tried” is an implicit struggle in adjusting; perhaps demonstrating a disparity between what is being asked of her and what she is mature enough to manage.

Further than levelling, participant 5 depicts an inversion of roles.

> Participant 5: “Um […] she […] they could be doing chores once that we complained about doing but now had to be done because she wasn’t able to do them herself, […] and she’d try and help but she’d be a hindrance and it was […] an inverted childhood.” (5.26.434-435)

He notes that these chores “had to be done”. The sentiment of there being no other choice is similarly echoed by the other participants. Describing his mother as a “hindrance” appears somewhat harsh and seemingly mirrors his circumstances; harsh and unfair.

Somewhat similarly, participant 1 speaks about struggling with her role following her father’s diagnosis.

> Participant 1: “I was very much trapped between being an adult in a situation and being a child” (1.25.427-428)

She is not simply in between childhood and adulthood but feels “trapped”, stuck in an inescapable situation, which potentially reflects the nature of her father’s terminal illness. She neither identifies with being a child or an adult, and there appears to be nothing in between. Her sense of being “trapped” again alludes to there being no way out.

A sense of doing what needed to be done, despite difficulty, is discussed by most of the participants.

> Participant 5: “From a day to day point of view of how to live, um […] it meant taking care of mum to a large degree, uh, which meant [….] well doing what was expected, she’d taken care of us so it was fitting and right as it seems.” (5.35.609)

Participant 5 conveys a sense of duty and obligation in caring for his mother. She has taken care of him and now he must take care of her. He presents this as “fitting and right”. In much the same way participant 6 presents taking on additional responsibility within the family as a fundamental commitment.

> Participant 6: “When your family needs and needs you to do something and you’re in a position to do it…, it makes you a bit of a shit person of you don’t [laughs]” (6.14.205-210)

Similar to participant 5, participant 6 seems to express that there is a right way and a wrong way to act. It may be that these participants draw on their familial commitment, sense of duty and what is right, to promote resilience and give them the strength to continue in the face of difficulty.

Notably, it was not just the participants who seemingly struggled to adapt to new roles and responsibilities.

> Participant 4: “[…] um, […] he struggled to be able to know what to do […] like […] just be a parent because it was always me mum who did all that” (4.17.275-276)
>
> Participant 4: “Um, so he was finding it very difficult to manage us, manage his emotions. Plus he went down to see me mum like […] um, twice, three times a day, every day when she was in the Hospice.”(4.17.275-276)

Participant 4 presents her father as being somewhat lost and overwhelmed as he struggles to meet her expectations; taking on the additional responsibilities previously held by her mother. She demonstrates empathy for her father as she reflects on the numerous pressures placed upon him. However, her list-like description of her father’s undertakings also appears to accentuate that caring for her and her siblings was one of many things her father was attempting to manage.

As the parent's illness progresses, they are less able to fulfil their previous roles and responsibilities, necessitating the help of other family members. The participants describe their new and acute sense of responsibility as being necessary and appropriate, and a strong sense of resilience is apparent. However, there is also a clear struggle to adjust and to adopt to responsibilities prematurely.

5.1.4 Protecting each other

The word "protect" or the insinuation of protecting each other was present within most participant narratives. It was frequently used within the context of communication within the family; particularly how distressing information was shared. It seemed to be linked to a common goal amongst family members of attempting to limit each-others distress.

> Participant 1: "I think there were a lot of things when you're a teenager and you go through something, whether it's illness or you know, anything that's going on in your parent's lives, they don't always tell you the full truth because they're trying to protect you […]" (1.12.189- 190)

For participant 1, looking back on her experiences as an adult provides an additional layer of insight. The use of the expression "full truth" alludes to an "incomplete truth" that she may have been told by her parents with regards to her father's illness. Yet, she does not use language with negative connotations such as lie or conceal, and thus a sense of understanding is conveyed; her parents' were trying to do something positive in not disclosing information and perhaps attempting to shield their children where possible.

Participant 2 similarly reflects.

> Participant 2: "I think he was probably just trying to protect us in a way. Once he passed away, we found out that he'd been to a funeral directors and he'd organised where he wanted to be buried, and even which way he wanted to be facing […]" (2.21.350)

Finding out that her father had been making plans for his funeral and burial was unexpected. Participant 2 described being kept in the dark about many aspects of her father's illness. However, whilst some of the participants expressed wanting more information, participant 2 did not. She rather expressed gratitude that her father had tried to make things easier on his family by limiting the information he gave them about his illness and death.

The concept of protecting each other was not just described in terms of parents protecting their children, but was also explored in terms of siblings holding back emotive information from each other and children attempting to protect their parents.

> Participant 3: “I never wanted to speak to my mum about it because I didn’t want to upset her […] it […] just upset her every time I spoke to her […]” (3.26.443-444)

Participant 3 uses extreme language to demonstrate that she never wanted to speak to her mother about her father’s illness as it caused her to become upset. She therefore attempts to prevent further distress by withholding information from her mother. This is seemingly reflective of a broader, more cautious communication style adopted within most of the participant’s families. However, what is highlighted by the participants is a divergence, whereby some would have wanted more information (the “full truth”) whilst others were grateful to be “protected”.

5.2 Super-ordinate theme: Grappling with adolescence and adjustment to loss

The participants reported some sense of difficulty or struggle in coming to terms with their parent’s diagnosis; whether it be in terms of understanding the seriousness of the diagnosis and its implications or a more abstract understanding of imminent death. The difficulties expressed by the participants in coming to terms with events are set within the context of their life stage; adolescence. All participants spoke about the complexities associated with being an adolescent alongside being the child of a terminally ill parent. Thus, this theme reflects the complex interplay between simultaneously negotiating these challenges.

5.2.1 Struggling/not wanting to understand

Participants reflected on difficulties in understanding and fully comprehending their parent’s terminal illness; reflecting on how their understanding at the time, as adolescents, was in some ways limited. Most had not previously experienced the loss of a significant loved one and some participants spoke about not wanting to see their parent’s illness as life-threatening, and thus maintained a misplaced sense of optimism. Participant 3 explores her struggle to comprehend the severity of her father’s illness.

> Participant 3: “I remember my mum saying “dad, dad’s very poorly, we’re gonna have to […] the […] the doctors don’t know what’s wrong but they think it’s something quite serious […]and I started not to worry, but like think, you just, I just don’t, I just never ever thought it was going to be something like that” (3.8.109-110)

Her emphasis on never and ever demonstrate her continued shock and disbelief. She stresses that even when the gravity of the situation was seemingly conveyed, she was unable to comprehend it. Participant 4 similarly reflects on the limitations of her knowledge.

> Participant 4: “Um […] a, again at this point, I didn’t, I didn’t know what a hospice was, I didn’t know that it, was for terminally ill, uh, people.” (4.5.56-57)

The word “know” was strongly emphasised by the participant. She did not know what a hospice was, and this piece of information was important. In hindsight, she can identify that at this point her mother’s illness was past being curable. This example demonstrates the potential for misunderstandings and misconceptions, particularly for adolescents, who may have limited understanding and yet may be less inclined to seek clarification.

Similarly, participant 5 expresses his lack of understanding around what meaning was ascribed to certain words.

> Participant 5: “[…] um, and I didn’t really know what the word meant, I didn’t know what the implications were […]” (5.5.60-61)

There is a sense with all of the participants that the concept of illness was understood, however, the severity of illness, the implications regarding treatment and recovery and the impact of the diagnosis were less so. This poses the question of whether you can adjust to something or prepare for something that you do not fully understand.

For participant 3, although her father’s illness was emphasized as being severe, she struggled to see it as such.

> Participant 3: “It was like an annoyance in my mind, like coz it wasn’t erm […] I just refused to see it as like a serious thing so it was just kind of annoying”. (3.12.189-190)

She explains how continued talk within her family about the illness caused her to become frustrated and annoyed. It may be that participant 3 did not want to accept the reality of her father’s illness and her lack of acknowledgment of it served as a defence. Conversely, she may not have been given information that was sufficiently clear and/or accessible.

For the majority of participants, their age and lack of prior experience presented barriers in fully understanding their parent’s terminal illness and its repercussions. It was also apparent that information provided was sometimes inaccessible. It may be that given their maturity, the adolescents’ understanding was taken for granted. Adolescents may also fear that seeking clarity would point to a lack of maturity. However, there is also a sense of not wanting to understand, and it could be seen that the adolescents sought to protect themselves against the severity of their parent's illness and its implications.

5.2.2 Finding a means of coping

Participants spoke about coping or trying to cope during their parent's terminal illness. However, there appeared to be a divergence in approach; from those who tried to hold onto a sense of normality and those who seemingly could not tolerate normality. For the participants who tried to carry on with usual day to day life, it seemed some comfort was derived from the stability and familiarity of the everyday routine. However, for two participants, the gravity of their parent's illness and their new circumstances meant it was almost inconceivable for life to continue as normal. This appears to have led to more escapist coping mechanisms; primarily the use of drugs and alcohol.

Participant 6 speaks about the necessity of carrying on during her mother's illness.

> Participant 6: "It was […] it was difficult but it was one of those things that when you're doing it you just sit and you get on with it." (6.15.228-229)

> Participant 6: "It's like […] there's no point in getting upset about it because it's an inevitability. In hindsight I did really, really struggle with it. And particularly after she died I really, really struggled with it. But just in the […] that moment then it was like well this is a necessity. It needs to be done. Just do it. Sitting and crying over it in your spare time isn't going to change anything."(6.15.228-229)

There is a sense that as an adult participant 6 shows a greater understanding of her younger self, reflecting on the difficulties and struggles that she encountered. However, the voice of her younger self is also present which appears to provide a glimpse of her inner narrative at the time of her mother's illness whereby "it needs to be done", "just do it". Her tone here is direct and even harsh as she positions expressing emotion as unproductive and almost self-indulgent.

Participant 1 similarly reflects on how maintaining normality and getting on with things seemed like the best option at the time.

> Participant 1: "I always thought the best thing to do was to, you know, be strong and to try and carry on as normal […]" (1.10.159-160)

Continuing life as normal may provide a degree of certainty and stability which had been taken away by the terminal illness. Yet, there is also a possibility that whilst she associates strength with carrying on as normal, she associates emotional distress and struggling to adjust with weakness.

Maintaining normality could also be viewed as a defensive behaviour, reflecting a failure to accept the seriousness of the circumstances and a desire to return to the way life was prior to diagnosis.

> Participant 2: "[…] I don't know, I was like, we just pretended things were normal, like we just got on like normal erm […]" (2.24.399-400)

For participant 2, the idea of pretending creates a sense of illusion or unreality. Although they are carrying on with life as though everything is as it was previously, it is not. The majority of participants appeared to resume normality or create the illusion of normality as a way of coping. However, for two participants this was not the case.

> Participant 4: "I sort of went off the rails and started taking a lot of drugs." (4.23.371-372)

> Participant 4: "Um, […] So I, I weren't […] I didn't give myself time to grieve." (4.23.371-372)

Going "off the rails" and taking "a lot of drugs" feels somewhat frenzied and chaotic which potentially mirrors participant 4's internal experience. Her expression that she did not give herself time to grieve suggests that she wants to push her emotions away by self-medicating. Her drug use may also reflect an unwillingness to accept the finality and reality of her mother's death as she opts to create a new world distinct from reality. Experimenting with drugs and alcohol and engaging in high-risk activities may be viewed as a normative part of adolescence, as they seek to push boundaries and pursue new experiences. Yet for participants 4 and 5, it appears directly linked to their experiences and a wish to escape from them.

Participant 5 speaks about the offerings of "different worlds".

> Participant 5: "Um, but I would, retreat into […] [inhales] the box if I was on my own is my preference, um, and different worlds offered their own, or, um, more concrete forms uh of flight, uh, mainly getting drunk, out and about or smoking weed or doing silly, bloody stupid things. I remember drinking petrol once which is something I never repeated." (5.28.470-471)

He speaks about "retreating into the box" and there is a sense of isolation and confinement. Yet he appears to associate alcohol and drugs with feelings of freedom. He potentially feels trapped in his situation and wants to escape from it, however his description of “different worlds” seemingly shows that he is aware that it is not reality. He cannot really escape. Doing “bloody stupid things”, such as drinking petrol, may suggest a contemplation of mortality and a more reckless attitude to his wellbeing. It may be that he now places a lesser value on life.

The two participants who spoke about using drugs and alcohol in relation to coping, also reported less close and supportive relationships with their surviving parent. Whilst this notably changed for participant 4, who described her relationship with her father as improving over time, their relationship both pre and immediately post bereavement was not a close one. Participant 5 equally described a more strained and distant relationship with his father, and both of these participants highlighted their terminally ill parent as a primary caregiver. Subsequently, perhaps a heightened and more overwhelming sense of loss was felt by these participants and a perceived lack of parental oversight.

5.2.3 “It was kind of an awkward difficult phase”

Participants referenced challenges associated with their age and life-stage during their interviews, presenting their age and experiences as being intrinsically entwined within this “awkward difficult phase”. Participant 1 reflects on the confusion and complexity of her internal and external worlds.

> Participant 1: “It’s that time you start going out to clubs, and getting drunk with your friends or getting your first boyfriend and all that kind of stuff and you’re having all these new experiences whilst all the other stuff is going on. It can be overwhelming […]”
>
> Participant 1: “that’s why I said I think it’s hard often at that time to articulate the way that you feel because there’s that much going on[…]you don’t really know[…]am I feeling like this because of dad or is it because I am stressed out about exams? […] or am I nervous about my driving test or because I’ve broken up with my first boyfriend? […] sometimes you’re not sure why you’re feeling that way […]” (1.43.735-748)

Presenting some of the milestones of adolescence serves to highlight the complexity of this life stage and creates a sense of being overwhelmed and confused. Parental terminal illness is not presented as a separate challenge but rather being added to the perplexity of the adolescent experience. Participant 1’s questioning stance potentially demonstrates a desire for understanding. However there appears to be significance in her questions remaining unanswered; as though there is no way of knowing the answers as her feelings are mixed together and cannot be separated out.

Participants spoke about how having a terminally ill parent created conflicting desires in wanting to be a “normal teenager”, whilst also being present and helpful at home. Participant 6 describes the interplay between these competing demands.

> Participant 6: “I was like god and I like got in a proper temper tantrum. And I was like I’m meant to be going to a music festival and dad like literally grabbed me and just like […] and this is literally the last holiday your mother is ever taking you are coming. And I was like, oh okay. (6.10.153-154)

A sense of being pulled back to reality is felt as she depicts wanting to spend time with her friends at a music festival. However, the realization appears to be that her circumstances are not ordinary and she has different priorities to others her age. The expression of “temper tantrum” alludes to immaturity, and the contrast between attending a music festival and going on a final holiday with her mother reflects the stark contrast of her reality.

Similarly participant 1 positions her father’s illness within the context of her life stage.

> Participant 1: “You know I’d just turned seventeen […] so I had quite a lot going on […] I was learning to drive, you know, I was doing my A Levels or my AS Levels […] you know all these things that are going on when you’re that age […]” (1.8.115-118)

The depiction of these events as a list, illustrates the number of preoccupations encountered during adolescence. It seemed important for the participants to convey that their parent’s terminal illness did not occur in a vacuum, and they could not place everything else in their life on hold. In some aspects they had to miss out on “being an adolescent”. It also appeared challenging for the participants to understand or articulate what or how they were feeling during this complex and confusing period.

5.3 Super-ordinate theme: Barriers to feeling supported

Whilst participants reported having particular supportive figures, such as their surviving parent or a close friend, there was a sense of not feeling supported in a wider sense by friends, peers and professionals. Barriers to feeling supported included: Finding other adolescents who could understand and relate to their experiences, perceptions of social stereotypes and stigma and limitations of support services. This superordinate theme therefore aims to highlight these barriers to support.

5.3.1 “No-one my age really knows what to do”

Participants reported that other adolescents struggled to understand and relate to their experiences. This led them to act in ways which were perceived as being unhelpful. Some drew unwanted attention to the adolescent, making them feel different. Others ignored the adolescent or their experiences, leading to feelings of isolation or stigmatization. Whilst others appeared to feign understanding which was perceived as disingenuous.

> Participant 1: “I think it became very divisive amongst myself and my friends […] I felt that there were […] my real friends and then my friends who […] couldn’t quite get their head around what had happened or […] couldn’t face talking about it.” (1.18.302-303)

Participant 1 describes how her father’s illness led to changes in her social group. Whilst there were some friends who were seen as supportive, there were others who were not. She presents some of her peers as struggling to “get their head around” her situation and others who “couldn’t face talking about it”. There is perhaps a sense of others being insensitive or unknowing in how to approach her or the topic of her father’s illness.

Participant 2 reports being reluctant in talking about her emotions with her friends.

> Participant 2: “I mean my friends knew […] they knew that my dad was poorly […] erm but I never really spoke to them about how I felt […].” (2.26.430-431)

There may be many reasons why she does not wish to talk about her feelings. It may be that she feels uncomfortable or self-conscious in expressing her emotions. She may also fear that others would not be able to understand. As being understood by others, appeared to be particularly significant to the participants.

> Participant 4: “cause if you speak to someone they say “oh yea, I understand it”, but they don’t understand at all […]” (4.34.538-539)

> Participant 4: “[…] what I’m going through unless you’ve sort of been there.” (4.34.538-539)

Participant 4 seemingly displays frustration towards others who pretend to understand what she is going through. Their comments seem disingenuous and almost insulting. How can they say that they understand something that they haven’t experienced? As other adolescents may struggle to relate to the participants, the participants may equally struggle to relate to them. The participants’ priorities, roles and responsibilities have changed and they may feel more mature than others their age. This enhanced maturity and the nature of their experiences may also make them feel fundamentally different from other adolescents.

In the main, adolescents appeared to find it difficult to know what to say, or how to act around the participants. The participants appeared to want to be understood by others, and this perhaps reflects a desire for their experiences and feelings to be normalized. Speaking to someone who has had a similar experience may thus be seen as comforting and reassuring. Perhaps also talking to someone who has had similar experiences creates a mutual sense of vulnerability and understanding which feels more bearable and comfortable than speaking to someone who has not had a similar experience.

5.3.2 Stereotypes and stigma

Participants also reflected on their perceptions of stereotypes and stigma associated with their parent's illness and death. Both the illness and death were depicted as taboo topics that were difficult to broach, and whilst the death of a parent became common knowledge, the illness that preceded it was frequently kept within the family. Thus, there is a sense that illness and death are both private and personal however they are also presented as socially awkward and uncomfortable topics.

Participant 1 describes the importance of other people's perceptions, specifically as an adolescent.

> Participant 1: " […] I didn't want to be[…]you know[…]ah this is the one who has the dead parent sort of thing[…] I think when you're younger, all the things that […] make you different from your friends, you maybe view them as negative […] (1.20.326-327)

The label "the one who has the dead parent", seems insensitive and immature and perhaps reflects how she perceives her peers as responding to her. She does not want to be stereotyped and viewed solely in relation to her painful experiences.

Similarly, she describes a perceived sense of social stigma attached to accessing counselling.

> Participant 1: "[…] obviously when you're that age […] counselling […] is […] a funny word I suppose. I think there's a lot of stigma attached to it. Erm […] I think […] probably not so much now that countries like the US […] it's quite common but I think in this country it's almost like a sign of […]of […] weakness." (1.6.84-85)

Counselling is depicted as something to be ashamed of. As though, asking for help demonstrates weakness. The emphasis on “that age” also alludes to a specific social environment associated with adolescence, whereby certain things are acceptable or unacceptable.

A similar sentiment is discussed by participant 5 within the context of gender.

> Participant 5: “It was offered to me at the time by my family, uh, retrospectively and again, I chose to decline it, partly because […] uh, partially the social environment where it says it’s not right for a man to cry or be upset.” (5.29.498-499)

He describes declining counselling on several occasions and the “social environment” appears of particular significance as he reports feeling that it is unacceptable for a man to cry or to be upset. Participant 5 has witnessed his mother’s terminal illness and death and yet feels unable to express emotions of distress and upset. Therefore, whilst he “chose” to decline additional support, there is a sense that his decision was based on an attempt to conform to perceived social norms and constructs around gender; which may have potentially served to pathologize his emotional responses to significant loss. The participants subsequently demonstrate potential barriers to support posed by their social and wider cultural environment.

5.3.3 [Counselling] “It’s a good concept”

Participants were asked during their interview to speak about their experiences and perceptions of support that they were aware of or accessed following their parent’s diagnosis. Whilst there were significant differences in each participant’s experiences in this regard, there appeared to be an overarching sense of support services being a “good concept” however in practice not living up to expectations in some way. Participant 4 describes a practical limitation of the support she received.

> Participant 4: “it took absolutely ages for me to get the appointment, um, but I had, I had to do it. I, I couldn’t […]”
>
> Participant 4: “But it was, it was really, really lengthy the time I had to wait” (4.30.472-478)

She expresses how she “had to do it” demonstrating her need for support. However, the emphasis on the length of time she had to wait appears significant. Perhaps it lead her to feel like her needs were not a priority.

For participant 1, the lack of age-specific support created a sense of being neglected or overlooked; impacting the perceived appropriateness or utility of therapy.

> Participant 1: “I think that you kind of think when you’re a child, you know, it doesn’t affect you in the same way. You spend more of your life, with that being the normality, I think when you’re an adult you understand things a bit more. I do think it’s […] it’s a difficult age group, but I think it’s good that you’re looking at it. As I said people can be, people think “target things towards children” but they, they think of smaller children rather than you know older adolescents and I think it’s hard. They’ve already got so much going on in their lives at that age.” (1.42.724-725)
>
> Participant 1: “They often get neglected […]” (1.42.724-725)

Her language is emotive as she describes how “difficult” and “hard” things can be at this age and her use of the word “neglected” demonstrates how she feels overlooked or excluded. There is a sense that there is no appropriate support available for her.

Participant 1 highlights challenges in working therapeutically with older adolescents.

> Participant 1: “[…] it was hard for me to, to really open up to her and talk to her because […] […] I think you often find yourself just telling a story. It’s not a dialogue as such, it’s not really in conversation[…]it’s just[…]you sit and tell somebody what’s happened[…]and I found that difficult to understand, I think because I was expecting her to give me answers to something.” (1.8.120-126)

She expresses how attending therapy was not a dialogue or a conversation and she found it difficult to make sense or use of this type of therapy. This reflects her previous excerpt which presents older adolescents as a challenging group whose needs are not met in terms of age-appropriate support.

Participant 5 described a different experience, expressing perceived constraints of time-limited therapy.

> Participant 5: “the first psychologist I saw was a, a, provided by the NHS and it just felt like it was a scenario whereby you are allocated six sessions and they wanted to have basically cured you of whatever ailed you[…] during those six sessions[…]” (5.31.532-533)

His comment appears almost flippant, as he presents the idea of being “cured of whatever ailed you”. His expression alludes to the fact that it did not seemingly matter what his difficulties were. Perhaps he felt that they did not matter and consequently he did not matter. The idea of six sessions is presented as constraining and perhaps he feels as though the magnitude of his experiences cannot be constrained in such a way.

Participant 4 expressed that counselling would not have been beneficial before or immediately after her mother's death.

> Participant 4: "I wanted to do it my way" (4.31.495-496)

She describes being "in denial" and "grief" and "trying to […] deal with my family and myself". It appears as though seeking help was another thing to do and to manage at a time where she already felt overwhelmed. She later notes accessing support years after her mother's death and finding it beneficial. Perhaps when counselling is offered immediately following bereavement, there has not been enough time for the adolescent to process their experiences or emotions. There may also be a propensity for adolescents to strive to be independent and not need support, which is intimated by participant 4.

Participants described seeking support from a psychologist or counsellor at some point following their parent's death. None of the participants received or were made aware of support available to them prior to their parent's death. Support or information provided in or via school/college was not mentioned. Moreover, some of the participants described negative experiences in terms of waiting times, the number of sessions or the type of intervention provided, and these downsides appeared to overshadow their experiences of the support received.

5.4. Super-ordinate theme: Living with the consequences

Participants spoke about the impact that their experiences of PTI had and continues to have on their lives. It became apparent through the interviews that the concept of loss was central to the participants' experiences both prior to their parent's death, post bereavement and presently. All participants described a variety of struggles or consequences of their experiences that they may not have had to contend with had their parent not become terminally ill. This superordinate theme therefore aims to highlight these past, present and future struggles.

5.4.1 Guilt and regret

Most participants spoke about how they looked back on their experiences with some sense of regret; exploring how they could have done something or responded to something differently. There appeared to be an ongoing struggle with guilt and regret amongst the participants and these feelings seemed difficult to manage.

> Participant 1: “You know he died eight, eight and a half years ago but I feel like there was a lot of things that weren’t said […]” (1.26.441-442)

For participant 1 there is an implication of regret or missed opportunity. The things that “weren’t said” can now never be said, and it may be difficult to accept the finality of that fact regardless of the time that has lapsed.

Similarly, for participant 4, there were things that were not said or done. She reflects on how an inability to comprehend the severity of her mother’s illness, meant that spending time with her was not perceived to be as precious and time-limited as in retrospect.

> Participant 4: “I think I had a lot of guilt that I’d been holding in over the years because of that; which I, I’ve only just felt[…] seeked, um, support for now, this year […]” (4.6.90-91)

She describes holding her guilt in and it feels difficult to talk about. The tone of her narrative changed at this point and she appeared more guarded than earlier in her interview. Her quickening pace perhaps suggests a further attempt to hide or hold in her feelings. It may be that her feelings of guilt are linked to embarrassment or shame, making them difficult to share. As she has only recently sought support, the continued force and impact of these feelings is apparent.

Participant 3 similarly expresses the potency of her feelings of ongoing guilt.

> Participant 3: “I’m really embarrassed with how I dealt with the whole thing I think it was, just […] appalling, I just really really ashamed of how I dealt with it […]” (3.24.409)

> Participant 3: “[…] from this point of view from what age I am now, that, that’s the most difficult thing to deal with” (3.24.409)

She appears to be reprimanding her younger self, as she describes her actions as embarrassing, appalling and shameful. She does not show her younger self understanding or empathy and her hard and direct language perhaps reflects an inability to forgive herself. She states that in the present, her guilt is the most difficult thing to deal with. This ongoing struggle with guilt was seemingly shared by most of the participants.

> Participant 5: “Incredibly shameful, embarrassing, guilty thing, [inhales] um, but you, how do you explain to your big sister or your loved ones who are around you, helping her survive and helping you cope the best you can, […] that you wanted her to die so that you wouldn’t have to feel pain anymore?” (5.21.348-350)

Participant 5 is critical of his younger self, and does not attempt to understand or empathise with him. It may be that he feels his thoughts were unjustifiable or unforgiveable. He presents others as being good and there is an implication that he is not. As he describes his sister and loved ones “helping her survive”, it almost seems as though he is implicating himself. Perhaps he feels some form of responsibility or culpability for his mother’s death.

Feelings of guilt and regret appeared to be pervasive for the participants and they did not seem to attempt to make sense of the thoughts or actions of their younger selves. In this way they appeared to lack empathy towards themselves. Their behaviour is presented as inexcusable and it may be that their inability to relinquish their guilt reflects their inability to forgive themselves.

5.4.2 New sense of mortality

Participants spoke about how their experiences denoted a fragility of life and a greater perceived awareness or preoccupation with death was apparent.

Participant 1 describes ongoing concerns about people becoming ill or dying.

> Participant 1: “I do worry about people getting sick, and people dying.” (1.38.652-654)

> Participant 1: “[…] but I think, I worry more about things I can’t do anything about […] I think it’s just […] yea […] I try and appreciate things at the same time, but at the same time I definitely worry more than I would like to […]” (1.38.652-654)

She notes her tendency to worry more about the things she cannot prevent, which may relate to a fear of powerlessness that may have been felt throughout her father’s illness. She also describes twofold realisations following her father’s death. The first is the worry inducing reality that people will continue to get ill and die and that loss will be experienced again. The second is that because life is not interminable it should be enjoyed and appreciated. However, to acknowledge and embrace both of these premises appears conflictual; as she tries to embrace and appreciate life however fears losing the things that make her happy and appreciative.

Participant 2 expresses similar worries.

> Participant 2: “I think in terms of the way I am with my family […] I don’t think I would be as I am now because […] I think definitely it’s changed me in that way […] because I feel very […] I’m really, I’m like a nervous wreck you know [laughs]

> especially with my little brother, I feel like though I'm I'm so overprotective and […] I worry about everything." (2.37.623-625)

The significance of family has perhaps been heightened by her experience of loss; amplifying how she values and cherishes her family. Equally, a significant fear around losing other people that she loves has also been induced. A preoccupation with illness and death is seemingly apparent amongst other participants.

> Participant 3: "I think as I've got older erm […] in the last few years I've had quite bad anxiety and things like that and I always thought that it might be a bit of a result of the fact that I didn't, because I didn't really think about anything at the time now I overthink everything and erm […] you know it's. if somebody that […]I never paid attention to you know anything complaints that my dad would have been ill or anything, but now I think that if somebody very close to me was complaining that they were ill, I would immediately think the worst and […] erm […] start worrying that something was going to happen." (3.30.513-515)

It appears that for participant 3 and the other participants, death has evolved from being perceived as an abstract concept to something that is not only possible but probable. From this, an anxious anticipation appears to have emerged, whereby in some respect the participants are continually waiting for something bad to happen.

5.4.3 Impact on education and life direction

The majority of participants spoke about how their experience of having a terminally ill parent impacted important decisions they were required to make as 16 to 18 year olds. This area of discussion was multifaceted but appeared to fall within the overarching title of this theme. Some participants reflected on how their experiences impacted their career path; through picking different A Levels or University courses that they may not have otherwise chosen. The majority of participants expressed wanting to work in a caring profession that they had not previously considered; such as nursing, support work and charitable domains. Some participants also spoke about how deciding whether to go to university or which university to go to became a complex process, with new considerations; such as whether to stay at home and not attend university or whether to study closer to home. Participants also reflected on how they were given more leeway from their parents and teachers, and some felt less importance was placed on academic performance.

Participant 2 considers the impact of her father's illness on her decisions as an adolescent.

> Participant 2: “well it did have a huge impact on, at that time, because you were thinking about obviously going to uni, and leaving home […]” (2.7.97)

> Participant 2: “[…] moving away, erm, I didn’t want to leave my family” (2.7.97)

“I didn’t want to leave my family” creates a sense of being pulled in two different directions. There is a feeling of pressure and responsibility, both towards her family and towards her education. Later in the interview Participant 2 describes feeling the pressure of living up to her father’s expectations following his death, as her family and friends express “it’s what your dad would have wanted”. Similar sentiments were expressed by the other participants. As such, parental illness and loss seemed to add an additional layer of complexity to the decisions the adolescents were required to make.

For participant 1, going to college and attending lessons appeared less of a priority than previously. In her interview she repeats that it is “not as important” and “definitely not the bee all and end all” due to “other stuff that’s going on”. She reflects therefore on how her perceptions of education shifted and how additionally less pressure was felt from others with regards to it.

> Participant 1: “[…] at school I think […] erm […] my teacher became quite accepting.” (1.17.282)

Her reflection on her teacher being accepting, seems both compassionate and submissive. It may be that her teacher is giving her space to grieve and adjust however it may also be that her teacher does not know how to respond. As such, a sense of resignation is conceivable.

A similar sentiment is expressed by participant 5, as he describes being given “leeway in life”.

> Participant 5: “And I think because […] of the fallout, from, mum having the cancer has almost given me too much leeway in life, like I was given just enough rope to hang myself with […]” (5.46.806-807)

Being given “leeway” is presented negatively as he associates it with his metaphorical demise. His expression of being given enough rope to hang himself with is poignant. Does he see his life as being in some way over? The finality associated with death suggests that there is no way back for him. This may represent feeling lost and unable to see a way out. Earlier in the interview, participant 5 described his mother as his anchor and his moral compass. This may suggest that her loss has led to a sense of rootlessness and a lack of direction. Thus, being given “too much leeway” by others may not have been helpful.

The participants' experiences appear to have impacted their values and priorities. For participant 5 this is reflected in his choice of career.

> Participant 5: "I do want to make a difference and there's simply no part wants to do a career, uh, for the sake of just monetary gain and the other things just don't mean too much to me." (5.44.767-769)

This idea of "making a difference" appears significant to all of the participants, some speaking about fundraising for charities associated with their parent's illness, some working in healthcare and one as a drug and alcohol worker. It may be that the participants want to give meaning to their experiences, by attempting to generate something positive from something negative.

> Participant 4: "we're all in the caring profession"

> Participant 4: "I'm sure we're all sort of driven by the emotions that we want to help people." (4.42.688-689)

It appears that for all the participants their experiences of parental terminal illness and death have had a lasting impact on who they are and how they live their lives.

5.4.4 The ongoing process of loss

Participants spoke about what their parent's illness and death meant for them at the time, and the meaning it continues to hold; presenting loss and grief as processes beginning around the time of diagnosis and continuing into their present and future lives. For all of the participants, it has been more than eight years since their parent's death and their lives have changed significantly since. The majority of the participants spent some time during the interview reflecting on the changes that have occurred in their lives and the absence of their parent during these changes.

> Participant 1: "[…] and I always think […] it's a shame he's not around now, because there are people in my life who […] have made me the person that I am now, or you know, like my boyfriend […] I would have loved […] I would have loved him to meet my boyfriend and I have best friends who will never, have never met him […]" (1.21.340-341)

The participants will not have their parent present for the main milestones in their life. Therefore, even positive life events are discussed with some sadness. Participant 1 reflects on how her father will not meet her boyfriend or her new friends. Her choice of language ("always", "never" "ever") seems to intensify her remarks. This potentially highlights the personal significance of what she is saying. There is also a poignancy of her tenses as she fluctuates between past, present and future which appears to illustrate the trajectory of her grief.

Similarly, participant 4 reflects on what has been lost.

> Participant 4: “later on, we, we started to get close again but obviously then she passed away, so […]” (4.16.246-247)
>
> Participant 4: “[…] there was a lot of wasted time really.” (4.16.246-247)

There is a sense here of what might have been and as with participant 1, a reflection on what now will never be. It may be that they are struggling to accept the finality of their parent’s death. Participant 4 expresses how she began to form a closer relationship with her mother before her death and her sentence is cut off; reflecting the premature end to her relationship with her mother which did not get a chance to run its course. Her expression of “wasted time” may suggest a lack of closure.

Participant 5 similarly demonstrates an ongoing process of loss and grief. He describes an unparalleled love for his mother and subsequently an unparalleled sense of loss following her death.

> Participant 5: “she was incredibly good and I’ve never, ever loved anyone as much as I loved her.” (5.25.431-432)

During his interview he spoke about the particular significance of his mother throughout his young life. He described his mother as a “ridiculously energetic and enthusiastic person” and shared moving anecdotes. His vivid description of her creates a strong sense of who she was and equally the void she has left; which seemingly cannot be filled.

5.5 Summary of findings

Analysis of participant narratives provides an exploration of how these individuals make sense of their experiences of PTI and death during adolescence. Their experiences of which are presented as complex, challenging and life-altering for adolescents and their families. There was an emphasis on how PTI impacted the family system, primarily in terms of roles, responsibilities and relationships; which necessitated processes of adjustment and reorganization. It was also stressed how being an adolescent impacted participants’ experiences of PTI and bereavement. In terms of understanding and coping with their parent’s prognosis as well as managing concurrent transitions associated with their developmental stage.

Analysis also explored what might be helpful or even unhelpful for adolescents impacted by PTI, particularly in terms of perceptions of support and help-seeking behaviours. For the participants, it appeared as though being an adolescent with a TI or deceased parent could be an isolating experience, with others of a similar age seeming less equipped to respond empathetically or supportively to their circumstances. Participants also raised the question of social acceptability around accessing supportive services and several barriers were presented in the way of having their needs met.

Given the retrospective nature of the study, analysis also gained insight into longer-term impacts of experiences, owing to which, participants not only expressed an ongoing sense of loss, but also ongoing guilt and worry. Participants also highlighted a relationship between their experiences and career choices; creating a sense that not only have their experiences of PTI and bereavement had and continue to have a significant impact on their lives, but also on who they are and what they do.

6.0 Discussion

6.1 Overview

This study aimed to explore the lived experiences of individuals who had a parent diagnosed with a terminal illness (TI) during adolescence, giving consideration to their perceptions and experiences of support during this period. Using an IPA approach, analysis yielded insights into these experiences from the perspective of six individuals. The results of the study generated four themes: Grappling with adolescence and adjustment to loss, changing family dynamics, living with the consequences and barriers to feeling/being supported. In accordance with the nature of IPA research, these views are representative of this particular group of individuals and findings from this study are not intended to be broadly generalizable.

This chapter will firstly consider the relationship between adolescence and parental terminal illness (PTI); considering adolescents' understanding of and coping with a terminal diagnosis as well as concurrent challenges associated with their developmental life-stage. Next, discussion will turn to the wider family system, where consideration will be given to changes in roles, responsibilities, dynamics and relationships brought about by a terminal diagnosis. Discussion will then focus on the potential longer-term consequences of PTI during adolescence, including ongoing difficulties as well as elements of growth and positive change. Consideration will then be given to the provision of supportive services in the U.K. as well as what, in terms of supportive individuals, services and interventions, may be of use to adolescents during this period, and what challenges may exist in terms of adolescents accessing and utilizing support.

Subsequently, the question of whether counselling psychologists can offer a valuable resource for this population will be broached; considering the potential relevance of the discipline's philosophical underpinnings, clinical practices and finally whether counselling psychology training in the U.K. lends to work in this area. Discussion will conclude with evaluating the current study and providing recommendations for future research.

6.2 Adolescence and parental terminal illness

As can be seen from the literature review chapter there is a notable lack of recent contemporary literature, which has been conducted in this area. In particular, few empirical studies have specifically considered how older adolescents experience and respond to parental terminal illness (PTI) and death (Grabiak et al., 2007; Lewis, 2007; Philips, 2014).

However, results from some studies (E.g. Rainville et al., 2012; Kuhne et al., 2012), seemingly suggest that experiencing the terminal illness of a parent during late adolescence may be distinctly challenging. For example, in Rainville et al.’s (2012) quantitative study of psychological distress among adolescents living with a parent with advanced cancer, older adolescents (aged 15 to 18) were found to experience significantly greater psychological distress than children or younger adolescents. However, as few qualitative studies have been conducted in this area (Grabiak et al., 2007; Lewis, 2007), it could be argued that the experiences of older adolescents facing PTI and death are not well understood. Thus, questions remain as to how older adolescents experience PTI and death and why they may experience greater psychological distress than those younger?

Results from the present study, broadly align with previous findings (E.g. Rainville et al., 2012; Kuhne et al., 2012) in indicating that there may be distinct challenges encountered by older adolescents with terminally ill parents. One such area of difficulty appeared to be understanding the terminal diagnosis and its consequences, and participants highlighted how language use, terminology and a lack of accessible information may have posed barriers to their understanding. Additionally, participants intimated a struggle to cope during their parent’s illness, and it appeared as though some participants were less equipped in terms of adaptive coping skills and strategies. Moreover, participants highlighted the relevance of their developmental context, in terms of age and life-stage; by presenting the concurrent challenges and transitions that they were attempting to negotiate (E.g. studying for exams, choosing career paths and/or forming intimate relationships). Thus, this section, derived from the superordinate theme “grappling with adolescence and adjustment to loss”, highlights the relationship between the participants age and experiences.

6.2.1 Understanding and coping with a terminal diagnosis

Corr (2010) and Biank and Werner-Lin (2011) assert that adolescents may be able to understand and conceptualise experiences of loss in more sophisticated ways than younger children. However, findings from Melcher et al. (2015) suggest that adolescents may struggle to understand and recognise factors specifically associated with parental illness. For example, adolescents may not anticipate various aspects of illness, such as symptoms, treatment and diminishing parental capacity (Melcher et al., 2015). Aligning with findings from Melcher et al. (2015), results from the present study intimate that whilst adolescents might be informed about their parent’s diagnosis, they may struggle to comprehend its significance and repercussions. Thus whilst participants expressed knowing that their parent had been diagnosed with a terminal illness, they described being unprepared for later stages of their parent's illness and even the bereavement itself.

A potential reason why adolescents may struggle to understand aspects of their parent's illness, may be the language and terminology used. Graham and Brookey (2008) argue that medicalised language, can be complex and inaccessible for patients, and this may be even more the case for adolescents (Blake, Weber and Fletcher, 2004); who have less prior knowledge and life experience. Seemingly in agreement with this, participants in the present study spoke about receiving limited or inaccessible information regarding their parent's diagnosis. They particularly expressed that the language used in relation to their parent's illness was difficult to understand, and they appeared to struggle with both medical terminology (E.g. Stage 4 Cancer) and contextual information (E.g. a parent moving from a hospital to a hospice). Thus, based on participant narratives, it could be argued that adolescents may struggle to fully understand PTI, potentially owing to their more limited knowledge and experience and additionally due to the information provided to them; which may not be clear, complete or age-appropriate.

However, results from the current study also suggest that it may be difficult for parents, guardians and healthcare providers to ensure that adolescents have an adequate understanding of PTI, as adolescents may be reluctant to ask for information or support. Malone (2016) contends that adolescents are likely to project an image of independence, not wanting to need adults, and findings from the present study similarly suggest. Participants reported being sensitive to feeling patronised by adults and seemingly did not want to highlight their lack of understanding, and consequently appeared unlikely to ask for clarification. Findings from prior research (E.g. Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; Turner et al., 2004; Turner et al., 2007) suggest that parents may struggle to inform and communicate with their children about advanced illness, particularly in deciding which information to convey, when to present it and what language to use (Houldin & Lewis, 2006; Turner et al., 2004; Turner et al., 2007). However, results from the present study intimate that communicating effectively with adolescent children about terminal illness might further be confounded by adolescents projecting an image of independence and understanding; which may lead parents and healthcare providers to incorrectly presume adolescent understanding.

An additional factor, which may lead adolescents to becoming inadequately informed about PTI, may be an unwillingness to accept the diagnosis. In this regard, some participants seemed not to want to face the severity of their parent's condition and the inevitability of their death. Therefore, these individuals attempted to avoid illness-related information, and rather sought to confirm their belief that their parent would get better. This could arguably be perceived as part of a grieving process, reflective of the stage of denial as outlined in “The Five Stages of Grief” (Kubler-Ross, 1969). However, it could also be understood as an avoidant coping mechanism; whereby in the short term, the adolescent is comforted and protected by their unrealistic perception that their parent will recover. However, in the long-term, the adolescent may be less prepared and more distressed upon bereavement.

With regards to “coping” more broadly, all participants spoke about attempting to adjust and cope during their parent’s TI, and there was considerable individual difference in this regard. Lazarus and Folkman (1984), in their study of stress, appraisal and coping, depict coping as all of the strategies individuals may use to manage stressful situations. Whereas coping skills, refer to active problem-solving strategies alongside emotional and behavioural strategies aimed at tolerating stress (Lazarus & Folkman, 1984). Within the current study, it appeared as though, some participants, exhibited more adaptive coping skills than others. Seeking practical help and information appeared useful for participants as did talking to a parent, family member or friend. However, these strategies were not employed by all participants, and some demonstrated converse strategies; such as aforementioned avoidance and social withdrawal.

Hasking (2007) suggests that coping strategies may be of particular significance for adolescents and Aebi, Giger, Plattner, Metzke and Steinhausen (2014) further pose that those with adequate coping skills are less prone to negative outcomes (E.g. aggression and criminal behaviour). Whereas individuals with inadequate coping skills, particularly avoidant coping, may be more susceptible to engage in criminal behaviour and/or substance use (Aebi et al., 2014). These findings appear particularly relevant given participant narratives in the present study. As those who spoke about feeling overwhelmed and unable to cope, seemingly sought to avoid unpleasant experiences, cognitions and emotions, and had a greater propensity to isolate themselves and furthermore, to engage in drug and alcohol use.

A further coping mechanism, described by participants, was a focus on maintaining daily life and routine. “Maintaining normalcy” was similarly identified by Issel, Ersek and Lewis (1990) as a coping strategy used by children of breast cancer patients. Although this study related to all stages of illness, not specifically the terminal phase, there appears to be a parallel; as four of the participants in the current study described maintaining normalcy as a primary way of coping with their parent’s illness. Attempting to maintain normality could perhaps be interpreted as a form of avoidant coping (Sigman & Wilson, 1998), as the individual may be attempting to deny that their normality has changed. Findings from Sigman and Wilson's (1998) study provide a caution in this regard, as they suggest that in the instance of parental death during adolescence, coping styles which may be seen as avoidant, are associated with later psychological distress. However, Helseth and Ulfsaet (2003) and Romanoff and Thompson (2006) propose that children may attempt to cope with their parent's illness by involving themselves with activities reflective of their life prior to the diagnosis and they suggest that this may not necessarily reflect a denial of reality; rather a useful distraction which prevents them dwelling on their parent's illness and its implications (Helseth & Ulfsaet, 2003). For the participants in the current study, it appears, maintaining normality (E.g. focusing on daily life and routine), provided both a useful distraction and a form of avoidant coping, dependent on the individual.

Overall, results suggest that adolescents may be susceptible to becoming inadequately informed about PTI, particularly in terms of being prepared for the later stages of illness and bereavement itself. Yet, it may be difficult to establish the level of an adolescent's understanding; given their outward demeanour and reluctance to seek clarification. Thus, it may be important for parents and those working with this group to take time in providing adolescents with clear and detailed information regarding PTI, including information preparing them for final stages of illness and bereavement. It may also be of benefit to ensure that any medicalised language or terminology is clearly redefined. Furthermore, results suggest that adolescents may employ a variety of coping mechanisms when a parent is diagnosed with a TI. More adaptive or positive coping mechanisms included, seeking information and support and talking to a friend or parent. Whilst less positive or maladaptive mechanisms seemingly included social isolation or the use of drugs and alcohol. Thus, it could be argued that having appropriate coping skills could be a risk or protective factor for adolescents of terminally ill parents, and an element that may be usefully assessed by those working with this group. It may also be of benefit to consider the purpose particular coping mechanisms may serve for the individual (E.g. Is maintaining normality an attempt to deny reality or a useful distraction?).

6.2.2 Developmental life-stage factors

A further factor, demonstrative of this theme, appeared to be the concurrent challenges participants experienced; both in terms of PTI and their life-stage. In this regard, the participants presented the difficulties associated with PTI itself, alongside those associated with normative developmental tasks. For example, learning to drive, studying for exams, choosing career paths and forming intimate relationships were discussed by participants and appeared to add to the overall complexity of this period.

In Melcher et al.'s (2015) study, adolescence is depicted as a stressful period where teenagers strive to create an identity independent of their families. However, the authors contend that having a parent diagnosed with a terminal illness potentially shifts the adolescent's focus back towards their family. Adolescents may therefore experience conflicting desires in wanting to spend more time with the unwell parent, whilst also wanting to gain greater independence (Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011). This is similar to findings from the current study, whereby on the one hand participants' described being pulled back towards their family, wanting to spend more time with their unwell parent and focusing on the demands and responsibilities associated with their parent's illness. Yet, on the other hand, they expressed how specific events and experiences, associated with their life-stage, also required their time and attention. It therefore appeared difficult for the participants to find a balance between focusing on factors associated with PTI as well as focusing on the factors associated with their life-stage.

It appears that this element of adolescent experience of PTI has perhaps received less attention in existing research than other areas, and this may be, to some extent, because only a relatively small number of studies have focused on adolescent experiences from their own perspective (Philips, 2014). However, The World Health Organisation (2007) report also suggests that there is often a mismatch in the perception of adolescent needs, whereby adults and service-providers potentially perceive adolescent needs differently to how adolescents perceive their own needs. In particular, the report contends that adolescents may require more support with normative developmental issues, and these needs frequently go unmet due to a greater focus on other contentious issues; such as drug and alcohol misuse and sexual health and behaviours (WHO, 2007). This report, therefore, highlights the importance of understanding how adolescents perceive their own need for support, and potentially also underlines the need for an increased focus on difficulties associated with more normative tasks and transitions.

In this regard, based on findings from the present study, it might be argued that adolescents of TI parents may benefit from additional help and support in managing what may be seen as normative developmental tasks and transitions. As not only may this be a challenging life-stage in its own right, but adolescents of TI parents face concurrent challenges at home, and their families and family resources may be focused on illness-related issues. Thus, adolescents may benefit from help in managing the factors associated with their life-stage, and in finding a suitable balance between family and personal life and responsibility.

Based on findings from the present study, it could also be argued that exploring the relationship between adolescence and PTI, may be of distinct importance. As participants' present PTI and life-stage factors, not as distinct issues, but rather as being intrinsically entwined. They expressed being unable to disentangle their complex emotional responses and decipher which of their emotions related to PTI and which related to elements of their adolescent experience (E.g. Participant 1 - am I feeling like this because of dad or is it because I'm stressed out about exams?).

This difficulty in teasing out whether elements of the participants experiences related specifically to adolescence or PTI and bereavement were also experienced by the researcher. For example experiencing intense and confusing emotions, social transitions and difficulties, family roles and relationships and even behaviours associated with risk (E.g. the use of drugs and alcohol) may all be associated with adolescence independent of PTI (Christie & Viner, 2005). As such, there was an inability to tease out which elements of experience related specifically to adolescence itself and those that related specifically to PTI. It might therefore be considered that developmental life-stage factors may form an integral part of adolescent experiences of PTI, and understanding how these factors interrelate may help researchers and practitioners in gaining a more holistic understanding of the challenges this group face.

6.3 The changing family

The centrality of the family system is highlighted in much of the literature and research in this area, and Bugge, et al. (2009) position that "the anticipated death of a parent from a terminal illness is a family crisis from any perspective" (Bugge et al., 2009, p.3487). Similarly, results from the current study suggest that PTI may impact all areas of family life, including roles and responsibilities, relationships and communication patterns. Participants described the impact of these changes on themselves as individuals, as well as their family as a whole. Thus, this section, derived from the superordinate theme "changing family dynamics", highlights these changing aspects of family life.

6.3.1 Evolving roles and relationships

An area of significant change, highlighted by participants, appeared to be related to the deterioration of their parent's physical and mental health, which seemed to alter interfamilial relationships and structure, and also increase adolescent distress. Contrary findings have been reported regarding the relationship between physical impairment of an ill parent and adolescent mental health (Compas et al., 1994; Lindqvist, Schmitt, Santalahti, Romer & Piha, 2007; Visser et al., 2006). Most studies that have been conducted have not included a control group (E.g. Compas et al., 1994; Huizinga, Visser, van der Graaf, Hoekstra & Hoekstra- Weebers, 2005; Welch et al., 1996) and thus conclusions may be difficult to draw (Lindqvist et al., 2007). However, some studies have reported that the impact of advanced parental cancer on patient's children was greater where physical symptoms were pronounced (Kennedy & Lloyd-Williams., 2009) and adolescent distress has also been associated with decreased mental health of the ill parent (Hoke, 2001; Lindqvist et al., 2007; Watson, St. James-Roberts, Ashley, Tilney, Brougham, Edwards, Baldus & Romer, 2006).

Aligning with these study findings, results from the current study also seemingly intimate a relationship between the unwell parent's physical and psychological symptoms and adolescent distress. The participants detailed parents' physical change and deterioration, from the loss of hair and weight to mobility and autonomy, as well as changes in temperament and personality; such as a perceived lack of interest or involvement in daily life, increased irritability or even changes in food preferences and tastes. The participants stressed how their parent was almost unrecognisable and it appeared as though witnessing this aspect of PTI was particularly distressing and anxiety-provoking. Christ et al. (1994) contends that adolescents have more advanced cognitive and empathetic capacities than younger children, rendering them more aware and attuned to their parent's physical and emotional pain than those younger, and findings from the current study seemingly offer support for adolescents' acute awareness of and sensitivity to their parents' pain. Also aligning with findings from Christ et al. (1994), participants described feeling frustrated and helpless in being unable to alleviate their parent's suffering.

Whilst it could be seen that parents' deteriorating health led to increased worry and distress for participants, it also seemed apparent that their worsening condition, rendered parents less able to maintain their household roles and responsibilities; which needed to be otherwise managed. In the current study, this gap was filled by the participants themselves, who seemingly transitioned into more responsible roles in an attempt to meet their family's needs. However prior studies (E.g. Christ et al., 1994; Folkner & Davey, 2002) have reported similar findings and Jantzer et al. (2013) further suggest that adolescent children of TI parents may take on a variety of new physically and psychologically demanding roles.

Aligning with findings from Jantzer et al. (2013), Christ et al. (1994) argued that in addition to household responsibilities, adolescents of TI parents may also take on nursing or caring roles; which may prove to be particularly difficult and upsetting. This finding was similarly highlighted by participants in the present study, who described taking on a variety of different domestic and caring roles; such as looking after younger siblings, assisting with meal preparation, cleaning and tidying, and providing care and support for both well and unwell parents.

Such findings are also in accordance with Melcher et al. (2015), whereby teenage participants described feeling responsible for their parents, siblings and everyday family life. They coordinated healthcare, comforted parents, and protected them from anything that may be exhausting or deleterious. As such, they were depicted as a “primary resource” for their parents (Melcher et al., 2015, p.4). Similarly, findings from the present study suggest that the participants became a “primary resource” for their parents and families. However, participant narratives also suggest that increased levels of responsibility led to a change in relationship dynamics; whereby parent-child relationships transitioned to become more equal, or in some cases an inversion of parent-child roles was intimated.

Despite apparent challenges, findings from previous studies (E.g. Christ et al., 1994; Jantzer et al., 2013) suggest that adolescents are mainly able to accept and adapt to newfound roles and responsibilities, and this is somewhat in accordance with findings from the present study; as participants expressed feeling able to manage new practical and domestic tasks with relative ease. However, conversely, participants also described how adopting supportive, nursing/caring roles, was not as easily managed, and it appears this element of assuming responsibility was much more psychologically and emotionally difficult for the participants.

Whilst many elements of family change, brought about by PTI, may arguably be seen as adverse, results from the present study suggest that there may also be the potential for positive change, growth and transformation. Prior research has suggested that a serious illness diagnosis may bring families closer together (Brennan, 2004) and allow them the opportunity to spend more time together (Elmberger, Bolund & Lützen, 2002). This was also intimated by participants in the present study, who particularly described becoming closer to their well parent. Notably, Lindqvist et al. (2007) hypothesizes that serious illness diagnosis may increase adolescents’ sense of gratitude towards life increasing their perceived value of family. This may be the case for the participants in the current study, who may feel a greater sense of parental value and appreciation. However, the participants did not just express enhanced appreciation for their existing relationship. They detailed how their relationship had evolved as they found new ways of communicating, understanding and relating to each other. Thus, their relationships did not remain the same, even when positive. Rather, it was somehow strengthened or enriched. It could therefore be argued that this denotes a process of posttraumatic growth (PTG), whereby difficulty and adversity have been found to elicit elements of positive change (Brewer & Sparkes, 2011; Jantzer et al., 2013; Tedeschi & Calhoun, 1996).

However, not all participants described experiencing a transformative relationship with their well parent. Some, rather appeared to experience a worsening of this relationship, and it seemed that this was particularly the case where it was felt that their needs were not being met. Harris (1995) put forward that when a child loses a parent, the surviving parent takes on an increased significance; as all of the child's needs and expectations are transferred onto their surviving parent. Perhaps therefore, it could be considered that a positive transformative relationship may be experienced where the surviving parent is able to meet these needs and expectations; as was the case for most participants in the current study. However, when they are unable, or perceived as being unable, to meet needs or expectations, adolescents may feel an acuter sense of distress.

With this in mind, it appeared from the results that participant distress did not necessarily relate to whether their mother or father became unwell, but rather the nature and quality of the relationships with both well and unwell parent were of significance. To illustrate this point, it appeared as though a particularly close relationship with the unwell parent may have amplified participants' sense of loss, and this was particularly the case where a strained or conflictual relationship with the well/surviving parent was depicted. Thus, the nature of the participants' relationships with their parents appeared to be of greater significance in terms of adjustment and coping than the gender of the parent who became unwell.

Melcher et al. (2015) reported that parents are teenagers' primary source of support when a parent is dying, and where adequate support is received from them, there is little need for additional support. Thus, warm and supportive parental relationships may serve as a protective factor for adolescents of ill or deceased parents (Philips, 2014) and may facilitate positive adjustment pre-and-post bereavement (Christ et al., 1994; Siegel et al., 2003; Kennedy & Lloyd-Williams, 2009; Melcher et al., 2015). This is seemingly consistent with findings from the current study, whereby participants depict the importance of a strong and supportive relationship with their surviving parent as particularly significant. When positive, it appeared to provide safety and comfort for the adolescents, limiting perceived negative effects of familial change and also seemingly aiding in adolescent coping and adjustment both pre-and-post bereavement. However, results also seemingly intimate that the lack of a close supportive relationship with the well/surviving parent may pose a potential risk factor for adolescents; whose sense of loss may be amplified.

6.3.2 Information-sharing and communication

A further element of family change, seemingly brought about by PTI, was that of information-sharing. Participants particularly highlighted how following their parent's diagnosis, information appeared to be less freely shared, and rather different family members were privy to different information; seemingly dependent on age. Yet, the majority of participants reported wanting more information about their parent's illness, and expressed wishing there had been more information-sharing and more open communication.

As previously stated, parents may experience difficulties in informing their children about PTI (Houldin & Lewis, 2006; Kennedy & Lloyd-Williams, 2009; Sheehan et al., 2011; Turner et al., 2004; Turner et al, 2007), and findings from Haber (1994) suggest that parent's conflict about which information to communicate with their children may lead some to wait until their children bring up the illness or ask specific questions. However, results from Melcher et al. (2015) suggest that if parents do not talk about the illness, their children may feel unable to, and this was echoed by participants in the current study. Participants expressed that when their parents avoided talking about the illness, they also avoided the topic, assuming it was something their parents did not want to talk about.

On the one hand, it is conceivable that parents may be concerned that exposure to upsetting information may negatively impact their adolescent children. However, findings from the current study rather suggest that receiving too little or unclear information may lead adolescents to feel more confused and distressed, and potentially less prepared for parental death. Miller (2008) similarly reported that the more information adolescents received regarding their parent's illness, the fewer psychological symptoms they experience. Perhaps it could therefore be argued, that parents may need greater support during periods of TI; specifically, in what and how information might be shared with their adolescent children. However, findings also intimate that what information adolescents want, and how it would best be communicated, may depend on the adolescent themselves. Therefore, parents and healthcare providers may benefit from working directly with adolescents, and engaging with them, to ensure that their individual needs are being met.

Results from the current study also intimate that what and how information is shared within the family may reflect wider inter-familial communication patterns. Participant narratives suggest that family communication patterns may change following a terminal diagnosis; with most describing a perceived reduction in open communication. Whilst prior research has demonstrated that PTI may impact communication patterns within families (Thastum et al., 2008), the current study further indicates that altered communication patterns may reflect family members' desire to protect and limit each-others distress.

Yet, Wong et al. (2010) contend that communication within families may be of increasing importance where a parent has been diagnosed with a serious illness (Wong et al., 2010) and open communication within families regarding illness has been linked to children's resilience and overall sense of wellbeing (Osborn, 2007; Rainville & Dumont, 2010; Thastum et al., 2008; Wong et al., 2010). Furthermore, some study findings (E.g. Tercyak, Streisand, Peshkin & Lerman, 2000) suggest that reduced information-sharing and communication may be linked to decreased family cohesion, even when motivated by limiting distress. Thus, it could potentially be argued that whilst families may attempt to protect each-other by limiting the information they share and the openness of communication (as in the present study), this strategy in the main, may not serve their aim but may rather hamper adolescent coping and adjustment and a wider sense of family connectedness. Healthcare providers and professionals working with adolescents impacted by PTI and their families may therefore consider how families share information and communicate about illness-related issues and some families may benefit from interventions aimed at increasing open discussion around PTI; which may promote adolescent understanding as well as an enhanced sense of family cohesion and support.

6.4 Living with the consequences of PTI and bereavement

Following parental death, young people will experience a period of bereavement, including periods of sadness and more intense grief responses (Kranzler et al., 1990), and Kalter et al. (2003) argue that eighteen months following bereavement, young people are considered to be, in the majority, well-adjusted; scoring comparably to national norms on measures of anxiety and depression (Kalter, et al., 2003). Conversely, a smaller number of children and adolescents will experience more pervasive difficulties in adjusting to the death of a parent, which may lead to psychological diagnosis (5th ed.; DSM–5; American Psychiatric Association, 2013; Bryant, 2014; Rapael, et al., 1990; Sigman & Kelly, 1998). The current study did not utilise any measures to establish the potential presence of psychological symptoms amongst participants. Therefore, comment cannot be made as to whether participants may be considered as largely well-adjusted or experiencing more pervasive difficulties. However, results from the study suggest that the impact and/or consequences of PTI during adolescence may be long-standing and far-reaching; thus giving rise to the superordinate theme of "living with the consequences".

Given the retrospective nature of the current study, between 8 and 10 years had passed since the participants' experiences of PTI. However, the participants spoke about how their experiences had and continue to have a profound impact on their lives. One element discussed, was a pervasive sense of guilt which appeared to have its origins in the period of PTI. Whilst participants cited a variety of reasons for their feelings of guilt and regret, most appeared to wish that they could change something about how they responded to their parent or their parent's illness. For instance, some expressed wishing that they had spent more time with their parent, others wished that they had reacted differently to something, or that they could take back something that they said or say something that they did not.

Guilt and regret are commonly cited reactions to the loss of a loves one (Stroebe, Stroebe, van de Schoot, Schut, Abakoumkin & Li, 2014), and Stroebe et al. (2014) assert that feelings of guilt frequently relate to people wishing that they could have done things differently; in preventing loss, taking a more active role in their loved one's care or in improving their relationship with the deceased. Whilst this aligns with results from the present study, participant narratives suggest that feelings of guilt and regret have not lessened over time. Rather, now as adults, participants appeared to be more aware and critical of their younger selves and their perceived failings.

Furthermore, a particularly emotive aspect of guilt and regret, appeared to relate to feeling ready for a parent to die. This subject has seemingly received limited attention in existing research, perhaps due to its sensitive nature. However, it was reported in Sheehan and Draucker's (2011) study, where adolescents of critically ill parents expressed wanting their parent's suffering to come to an end. A similar wish was described by participants in the current study, however, one participant also spoke about how they perceived their parent's death as also bringing an end to some of their own suffering. This was a particularly difficult area of discussion and the participant depicted it as an "incredibly shameful guilty thing". This aspect of experience appeared to be very difficult for the participants to speak about, and it may be worth considering whether their hesitance relates to associated feelings of guilt and shame.

Results from the present study, also seemingly intimate that fear or anxiety around personal health and the health of loved ones may be a consequence of PTI and bereavement during adolescence. In this regard, participants expressed how their experiences led illness and death to become more than abstract concepts but rather potential and probable life occurrences. Thus, it could be seen that PTI altered participants' world-view; whereby the world was subsequently seen as a more anxiety-provoking place where anyone could become ill or die. Similar findings were reported by Philips and Lewis (2015), who reported that adolescents (aged 11-15) who had a parent with advanced cancer expressed feeling worried that they too might get cancer. It is however important to note that no measures for anxiety were utilized as part of the present study and comment cannot be made as to whether the participants' experience, previously or presently, any particular level or type of anxiety.

It may also be worth considering participants' experience of anxiety in terms of attachment theory (Bowlby, 1969, 1980). Patterns of behaviour associated with attachment style and the relationships to which they lead are thought to be present and active throughout the life cycle (St. Clair, 2000) with long-term consequences of childhood attachment style being documented (Hazan & Shaver, 1987; Feeney, 1999). However the stability of attachment representations across the life span have more recently been debated (Stroebe, Schut & Stroebe, 2005). Early personal and family dysfunction have been identified as potential disruptions which may impact the development of coherent views of self and others and subsequently lead to insecure attachment in adulthood (Cicchetti, 1991; Davila, Burge & Hammen, 1997). However, it has also been asserted that attachment style may be impacted by significant life events, although findings have been inconsistent in this regard (Kirkpatrick & Hzan, 1994; Baldwin & Fehr, 1995; Scharfe & Bartholomew, 1994; Stroebe, Schut & Stroebe, 2005). However, it may be worth considering in the context of the current study, whether PTI and bereavement during adolescence may have led to an altered attachment style; whereby participants may be less securely attached following their experiences. It is conceivable that individuals may either become overtly concerned about losing loved ones; seemingly demonstrating a more preoccupied attachment. Or alternatively becoming less likely to form new close relationships for fear of being hurt; perhaps demonstrative of a more dismissive attachment style.

A further consequence, identified from the present study, appeared to be the potential impact of PTI on adolescents' education and life-direction. McNamara (2000) contends that adolescents are required to make decisions which may hold important and oftentimes irreversible social and occupational consequences in adulthood. In agreement, participants in the present study expressed how some of the decisions they made during adolescence, continue to impact their lives. Moreover, some reflected on how PTI impacted these decisions, describing how they made choices that they would not have otherwise made (E.g. attending university closer to home or deferring attendance). Others expressed how education held less importance for them following their experiences, and subsequently academic achievement became less of a priority. Whilst this may arguably be seen as a negative consequence of PTI and bereavement, participants notably expressed how they felt that their experiences and changing priorities led them to a vocation; with most working in caring roles or charitable domains.

Existing literature, (E.g. Brewer & Sparkes, 2011) has explored the relationship between life adversity and altruism and Schultz (2007) suggests that adolescents who experience premature parental death, may strive to give meaning to their experiences which may fuel a sense of purpose. Similarly, Brewer and Sparkes (2011) reported that bereaved children had a propensity for altruism, seeking to help others and care for those in need. It could be argued that these findings are also reflected in the current study, insofar as following PTI and bereavement, participants' beliefs and goals appeared altered and they formed new priorities including a desire to help others.

Thus, overall, results suggest that the impact and/or consequences of PTI during adolescence may be broad and long-standing and adolescents may require support during periods of PTI and also following bereavement. Interventions aimed at addressing and alleviating feelings of guilt and shame may prove useful as well as interventions focusing on health-related anxieties. Furthermore, adolescents may benefit from help in navigating their future, particularly in making decisions which may affect their future lives and careers.

6.5 Support and support-seeking

One of the aims of the present study was to explore adolescents' experiences of support; considering what, in terms of supportive individuals, services and interventions, may be helpful or even unhelpful to adolescents during this period. Discussion was multifaceted, however there appeared to be an overarching element of difficulty in gaining adequate support both prior to and following parental bereavement. This section is therefore based around the superordinate theme "barriers to feeling/being supported" and aims to consider the wider context in terms of the provision of supportive services in the U.K. as well as how adolescents may perceive and experience supportive others, based upon participant narratives.

6.5.1 A mixed economy of care

Ackerman and Statham (2011) argue that for therapeutic intervention to be effective in supporting bereaved young people it must be appropriate to their circumstances, including age and stage of development as well as degree of distress and the presence of protective factors in their environment. In agreement, results from the present study similarly intimate the importance of assessing and understanding individual factors when working with adolescents of TI parents. Particularly, participant narratives highlight the complexity of PTI during adolescence, and the necessity of considering how factors such as increased responsibility at home, understanding and coping, developmental changes and transitions, and family relationships and processes may present particular challenges during this period. It also appears important to consider how these factors vary from person to person. As, in the present study, some participants demonstrated different levels of understanding regarding their parent’s diagnosis, different coping mechanisms, levels of responsibility and variations in family relationships and dynamics. Thus, it could be argued that in terms of supportive services and interventions, what may benefit one adolescent may not benefit another.

Aligning with this assertion, Sim, Machin and Bartlam (2014) argue that due to the variable and individual nature of grief and loss, bereavement care should not be provided on a “one-size-fits-all basis”. Rather, a range of supportive services and interventions may be of benefit. Similarly, results from the present study intimate the potential utility of a variety of supportive services and interventions targeted towards adolescents impacted by PTI. For example, providing accessible and age-appropriate information regarding PTI and bereavement may be of use, as might interventions focusing on developing adaptive coping skills, or therapeutic interventions aimed at improving family communication and cohesion. It should also be considered that whilst some adolescents may not require professional support, others may benefit from several such interventions or approaches. It might therefore be argued having access to a variety of services and supportive interventions may be useful for adolescents facing PTI, however it is perhaps of foremost importance that support be provided based on the specifically assessed needs of the individual.

The need for a variety of supportive services and interventions for the bereaved was similarly presented by Linda Machin in an interview for Bereavement UK (Bereavement UK, 2016), where she argued that grief should be recognized as a unique and variable experience necessitating therapeutic interventions as well as more informal types of support; which may together provide a mixed economy of care based on assessed need. Whilst findings from the present study seemingly offer support for Linda Machin’s position, results also highlight the need for greater consideration of pre-bereavement periods and the provision of support for those facing an impending bereavement.

Currently within the U.K., childhood bereavement services are provided across a range of domains, from public health and social services to hospices and private programmes (Rolls & Payne, 2003), meaning that it is difficult to gain a clear picture of bereavement services and the overall provision of support (DoH, 2011). Challenges are further apparent when considering pre-bereavement care, which may be provided through hospices, palliative care units and private programmes. However, it could be argued that there is a predominant focus on the provision of care following bereavement and fewer resources are available prior to bereavement. Providing further support for this assertion, only a small number of intervention studies have been carried out which aim to establish services or interventions for adolescents facing PTI (Philips, 2014). Yet, findings from those carried out (E.g. Bugge et al., 2009) seemingly suggest their usefulness.

Whilst there are resources available to young people effected by PTI, such as those provided by hospices or for example, the U.K. charity Hope Support Services (Hope Support Services, 2017), it is difficult to assess what services are available where and what they offer (DoH, 2011; Rolls & Payne, 2003). This raises questions around service accessibility and effectiveness which could potentially be explored through future research and service-evaluation. However, based on findings from the present study, it appears as though adolescents of TI parents face a multiplicity of changes and challenges prior to parental death and subsequently services offering a range of formal and informal interventions may be of significant value.

6.5.2 Adolescents and support-seeking

Whilst participant narratives intimate the potential importance and utility of support both prior to and post bereavement, results also suggest that adolescents may have a complex relationship with support-seeking, and that whilst parents, family members, teachers, friends, peers and healthcare providers may all be potential sources of support, there may also be particular barriers in terms of adolescents asking for or gaining the support they need.

As previously noted, Melcher et al. (2015) reported that parents are teenagers' primary source of support when a parent is dying, and where adequate support is received from them, there may be no need for additional support. Yet, other studies (E.g. Grabiak et al., 2007; kuhne et al., 2012) demonstrate that children of unwell parents may conceal their thoughts and feelings in order to protect their parents, with Kuhne et al. (2012) speculating that this may particularly be the case in instances of PTI. Findings from the current study are seemingly in agreement, as participants spoke about not wanting to worry or burden their parents with their distress. Rather, they appeared to hide the extent of their difficulties from parents. Such findings raise the question of whether parents can understand and adequately meet the needs of their adolescent children, in terms of support, if their children do not convey the extent of their upset and concerns.

However, adolescents may not just rely on parents for support. Friends and peers may also be a central source of support for adolescents. In the current study, participants described examining their friendships and some chose a select friend to confide in. These individuals were seen as being trustworthy and dependable and the participants perceived them as being understanding and empathetic. Gray (1989) linked better perceived social support to lower levels of depression, and in the current study, those who described having close friends to confide in appeared to feel more supported and socially embedded. However dependable, trustworthy and empathetic friends were presented by participants as exceptional, and in the main, they expressed feeling that most adolescents of the same age struggled to understand or know how to respond to them. This led them to feel uncomfortable and different from most of their peers, which is in accordance with prior research findings (E.g. Thompson and Payne, 2000; McCarthy, 2006).

Adolescents may in general, have less experience of serious illness and death than adults, and may be less prepared to respond to those who have. Furthermore, the provision of bereavement support and education in schools in the U.K. has been depicted as highly variable (Chadwick, 2011; Cranwell, 2007; Holland, 2001, 2008; Goddard, Smith & Boycott, 2013; Potts, 2013; Holland & McLennan, 2015; Holland & Wilkinson, 2015); with a large number of schools providing "reactive measures" (Holland, 2008, p.411); such as referring an individual to a school or external counselling service. Whilst this may be of benefit, it could be argued, based on results from the present study, that further "proactive measures" (Holland, 2008, p.411) may also be of benefit. Further educating young people on topics such as critical, terminal, chronic illness and bereavement may potentially aid in encouraging understanding and empathy, leading adolescents to feel more supported and be more supportive of their peers. It may also serve to lessen any stigma or social awkwardness surrounding these topics, which was also highlighted by participants in the current study.

A sense of stigma or social awkwardness was also discussed by participants in relation to accessing supportive services. They described how, as adolescents, it was felt that counselling was seen as something atypical, and perhaps something to be embarrassed about. Moreover, one participant spoke about the potential role of gender stereotyping, or perceptions of gender stereotyping. This participant was the only male participant in the study, and he spoke about how, as a male, he felt less able to demonstrate emotion and ask for help when he needed it because of his gender. Although a number of studies (E.g. Huizinga et al., 2005; Raveis & Siegel, 1999) have suggested that males may experience less distress than females when a parent is unwell, the experiences and perceptions of the male participant in the current study add credence to the question of whether males may be less likely to show or report distress than their female counterparts.

Stinson and Lasker (1992) contend that men may exhibit fewer grief responses, in part, due to gender stereotypes which denote that men should be strong and unemotional. However, it could be seen that these notions may hinder adaptive coping, particularly in males (Stinson & Lasker, 1992). Some researchers have labelled gender differences in grief responses as more typically “masculine” and “feminine” (Corr, Nabe & Corr, 2000; Nolen-Hoeksema & Larson, 1999; Stinson & Lasker, 1992). However it has been noted that so-called “feminine” grief responses, such as more open displays of emotion, support-seeking and sharing emotions with others may be more helpful in the grief process (Staudacher, 1991). As such, it could be argued from this perspective that grief responses identified as “masculine”, such as a failure to express or share ones emotional pain, may be more indicative of less favourable adaption to loss (Stinson & Lasker, 1992).

Seemingly in agreement, the male participant in the current study appeared more uncomfortable in overtly demonstrating emotion, and subsequently he seemed more likely to withdraw when upset as opposed to sharing his emotional grief responses with others. Similarly, it appeared as though the participant’s perceptions of maleness or masculinity posed a barrier in terms of accessing supportive services. Thus, whilst western social and cultural constructs around gender may be becoming less rigid than previously (Aros, Buckingham, & Rodriguez, 1999; Bierhals, Prigerson, Fasiczka, Frank, Miller & Reynolds, 1996), results from the present study seemingly intimate the potential influence that gender and social and cultural constructs around gender may continue to have in the grief process.

Aforementioned participant perceptions of stigma and stereotyping may also go some way to explain why only a minority of adolescents with mental health problems access treatment, as the reasons for this are currently not well understood (Reardon et al., 2017). Services such as Children and Young People Improving Access to Psychological Therapies (CYP-IAPT) place significant emphasis on service-user experiences, and a small number of research studies have explored the experiences of young bereavement service-users (E.g. Rolls & Payne, 2007). However, if young people in need of support are unlikely to access it (Reardon et al., 2017; WHO, 2007) it seems important to consider both perceptions and experiences of service-users and non-service-users; as was attempted in the present study.

Results from the study suggest that there may be a variety of different reasons why adolescents may be reluctant or opt not to access supportive services (E.g. perceptions of social acceptability and stigma or not wanting to be seen as needing support). However, participant narratives also intimate that there may be a number of reasons as to why adolescents disengage from services, or furthermore, fail to benefit from them.

All participants expressed how the idea of seeing a counsellor or psychologist for therapy appealed to them on some level. It appeared as though the anonymity of speaking to someone removed from their daily life was viewed as a positive, as was having a time where they could express how they felt without worrying about any repercussions (E.g. upsetting their parent). However, in practice, the participants expressed finding that the services offered to them did not live up to their expectations. As an example, some participants reflected on lengthy waiting times and a seemingly constricting number of sessions offered by NHS services. It is well known that Mental Health Trusts in the NHS have long waiting lists for psychological therapy, and in previous years, waiting times could be more than two years (James, 2011). However, it appeared as though, beyond a practical level, lengthy waiting times and a small number of sessions offered, may have communicated to the participants that their need was not great or perhaps that they were not a priority. Participants also spoke about struggling to build rapport with their therapist, and a sense of not feeling understood was intimated. Such findings may be of significance, as the WHO (2007) reports that adolescents who have had a dissatisfactory experience of supportive services may not consider accessing services again in the future, irrespective of need.

Overall, results suggest that whilst adolescents may have greater access to a wider variety of different supportive outlets than younger children (E.g. family, friends, peers, teachers and professionals) (Christ et al., 2004), they may have a complex relationship with support-seeking. In some instances, they may struggle to gain the support they need from family and friends and may likewise feel reluctant or unable to access supportive services. Furthermore, practical limitations of services and a struggle to establish rapport and feel understood by the therapist may further impede potential benefits for some adolescents, or may similarly lead to service disengagement. Despite this, it appeared as though the idea of psychological therapy appealed to all of the participants, particularly in terms of speaking to someone independent of their family and life, as well as having an open and safe space to express themselves.

6.6 How can counselling psychologists contribute to work in this area?

Children and young people’s mental health has been highlighted in recent times (Fonagy & Clark, 2015) with a focus on the benefits of early and effective treatment (DoH, 2011). The Department of Health (DoH, 2011) reported that one in ten children aged 5-16 has a clinically diagnosable mental health problem, and significant government funds have been earmarked for investment into psychological therapies for children and young people. The aim is to ensure that young people receive the best possible treatment, which is responsive to their needs (DoH, 2011). With increasing funding, expansion of services and overall attention given to this population, counselling psychologists may wish to draw attention to their ability to work effectively with this population; highlighting how they may offer a significant and unique contribution to working with young people.

When considering what counselling psychologists may contribute to work in this area, attention should be paid to the philosophical values of the discipline. Underpinned by humanistic values, Strawbridge and Woolfe (2010) proffer that counselling psychologists focus on "being with" as opposed to "doing something to" clients (P.10-11). This position emphasizes the importance of the therapeutic relationship in client work. Given that adolescents may be a difficult group to engage, a focus on the therapeutic relationship may be of particular significance. As demonstrated through findings from the current study, adolescents may have a complex relationship with adults, and may be reluctant to ask them for help. Findings further intimate that a negative experience of psychological therapy may prevent adolescents from engaging with services in the future. Bremner (2009) therefore poses that the biggest task of working with adolescents is to engage with them. Thus, a focus on building and maintaining a strong therapeutic relationship, which is central to counselling psychology (Strawbridge & Woolfe, 2010), may be of particular importance in working with this population. Furthermore, building rapport and a strong therapeutic alliance may enhance adolescents' feelings of safety and comfort; enabling them to speak more openly about this sensitive and emotive topic.

Results from the current study also suggest that as processes of grief and adjusting to PTI and loss are highly individual, a more dynamic and individualized approach may be most appropriate when working with this group. Similarly, Geldard and Geldard (2010) argue that in order for therapy to be constructive with this age-group, it must be tailored to the adolescent's need. Thus, a pluralistic framework, advocated by counselling psychologists may offer a constructive framework for working with this population; as it acknowledges that people may need different support at different times, and thus different therapeutic methods will be most useful for different clients at different points (Cooper & McLeod, 2007). Therefore, counselling psychologists, through adopting such a pluralistic framework may work with flexibility in their practice; utilising different approaches, based on literature, research and the assessed needs of the individual.

Whilst counselling psychologists may not be averse to the medical-model, and time-limited and more directive approaches, may be integrated as part of their practice. It could be argued that counselling psychologists, have more freedom than other disciplines to practice without the constraints of the medical model (Danchev, 2010). James (2011) further argues, that counselling psychologists “work in the language of formulation and not the language of diagnosis” (p.375). Focusing on formulation as opposed to diagnosis may help to give meaningful representation of adolescent experiences; highlighting their individual and unique responses and avoiding potentially pathologizing them. Working in this way highlights counselling psychology’s continued emphasis on individual subjective experience (Sinitsky, 2010), something that may be of great importance to adolescents; as participants in the current study stressed the importance of feeling understood by others and particularly in a therapeutic context.

Another way in which counselling psychologists may be well equipped to work with this population, is through their holistic approach to working with clients. Predominantly manualized and standardized approaches may not fit comfortably with counselling psychologists (James, 2011), and similarly, working purely with what may be described as the presenting issue (E.g. depression or anxiety) and not underlying or interlinking factors may be seen as incongruous with a belief in the importance of engaging holistically with the client and their individual subjective experience. This may be particularly important given the seeming complexity of PTI and bereavement during adolescence; where focusing on one element of experience may arguably be insufficient. As depression, sadness, anxiety, guilt/regret, rootlessness, directionless, and systemic issues may all be significant and to address one may fail to validate the complexity and uniqueness of the individual’s experience.

Furthermore, results from the present study seemingly suggest that PTI during adolescence may not only be a distressing and stressful experience, but one that may also hold long-term consequences. In limiting long-term psychological consequences, Durlak et al. (2010) stress the overall importance of early and focused interventions, which they argue may limit the extent and duration of difficulties and improve functioning. Thus, it is arguably congruent to working with this population that the discipline of counselling psychology, emphasizes the importance of providing early intervention to foster development in children (Sinitsky, 2010); emphasising processes of growth, change and development (Davy & Hutchinson, 2010). Based on results from the present study it may be worth considering whether such early interventions during periods of PTI may not only reduce adolescent distress and help them negotiate difficulties, but also equip them for future challenges.

Finally, and significantly, counselling psychologists seek to be attentive to the problems and possibilities that difficult experiences may evoke. Drawing on and promoting potential individual growth factors may prove particularly useful in bolstering resilience and growth in the circumstances of PTI and bereavement, as results from the current study demonstrate that resilience and growth may form an integral part of adolescent experiences of PTI and bereavement. For example, participants appeared to display growth and resilience in adjusting to significant responsibility, developing enhanced relationships and demonstrating a greater propensity for altruism. However, those working with this group must be cautious not to devalue or undermine the significant and distressing nature of this experience, but rather acknowledge that devastation and growth can exist simultaneously and to work with these factors as they fluctuate and change over time.

6.6.1 Training and professional development in counselling psychology

In the introductory chapter of this thesis, it was noted that working with issues relating to loss, grief and bereavement may form a large part of the work that counselling psychologists engage in. On the BPS directory of chartered psychologists (BPS, 2017), all registered counselling psychologists detail working with grief and loss as within their remit. Yet, there is a limited focus within the professional doctoral training on the theoretical, empirical and clinical implications of grief related issues. Counselling psychologists also currently contribute a limited amount to the large base of literature and research carried out in this area. Moreover, the role of counselling psychologists working with children and adolescents is also a point of contention.

Unlike the clinical psychology training, there is no core clinical placement with children and families and in fact until recently there was a cap on the number of clinical placement hours with children that could be counted towards qualification (BPS, 2014). Thus, Riha (2010) argues that working with children is an area frequently overlooked in counselling psychology training. It therefore seems important to consider whether counselling psychology training equips trainees for working with young people.

In terms of the approaches utilised in working with children, there appears to be few empirical studies demonstrating the effectiveness of one specific approach over another (Downey, 2003; Riha, 2010). However, cognitive behavioural therapy (CBT), psychodynamic/ psychoanalytic, humanistic/ interpersonal and creative therapy have been reported as effective for work with this group (Harris & Pattison, 2004). As counselling psychologists are typically trained in three of these key modalities; the humanistic, psychodynamic and cognitive behavioural approach, they may have the training and skills required to work with this population in terms of the specific and integrative approaches they may offer.

However, whilst counselling psychologists may have the skillset to work with young people, Davy and Hutchinson (2010) argue that working with children has a lower profile in the division of counselling psychology than working with adults. However, Sinitsky (2010) proffers the view that counselling psychologists may have much to offer in working with young people, even though the discipline itself is not altogether associated with working with children. It seems that in training, research and practice, counselling psychology is not a profession that emphasises working with children. Further beyond the previous cap on placement hours and the lack of a specified children's placement, the HCPC Standards of Proficiency for Practitioner Psychologists (2013) specifies understanding psychological models for children as a competency for clinical psychologists but not for counselling psychologists. Thus, it seems understandable why counselling psychologists may feel more comfortable and qualified to work with adults.

Yet, there seems to be a lack of congruity between how the discipline is presented and how it manifests in a real-world sense. For example, on the BPS Website it states that "Counselling psychologists work with both adults and children across a diverse range of issues, such as bereavement, relationships, mental health problems, etc., and aim to explore the underlying causes behind them" (BPS, 2017). In this short definition, working with children and working with bereavement are both mentioned, however in training and practice there seems to be a discourse around whether counselling psychologists do and should work with children.

One perspective is that working with children forms a specialist area of practice requiring supplementary teaching and training (Kegerreis, 2006). Thus, those counselling psychologists interested in pursuing a career in this area may opt to engage in independent supplementary learning and Continuing Professional Development (CPD) to further equip themselves for work with this population. However, the BPS CPD Approval Scheme, specifies only a small number of programmes and events that relate to working with children and seemingly non that relate specifically to adolescents. It therefore appears, that counselling psychologists, must independently seek the training, experience, supervision and professional development that they require to work and work effectively with this population.

This study has focused on the experiences of PTI during adolescence and perceptions of support. Whilst an argument has been outlined for a potential role of counselling psychology in this field, no claims can be made about their effectiveness or real-world contribution. However, given the apparent debate around whether counselling psychologists work with children, it seems important that the discipline seeks to define its position. Furthermore, in The Good Childhood Inquiry (Dunn & Layard, 2009), authors suggested that there are not enough mental health professionals working with children and adolescents in the U.K. and statistics of children's mental health further imply that there are increasing numbers of young people requiring psychological support. Riha (2009) suggests that this is a gap that counselling psychologists could potentially help to fill. The present study cannot offer empirical support for this assertion; however it does seem important, particularly with an increased emphasis on child and adolescent mental health, for counselling psychologists to contribute to this area and further attest their potential and real-world value in working with young people.

6.7 Limitations

The results of the present study have emerged from investigation carried out by one researcher, exploring the subjective experiences of a small group of six participants; as such no claims can be made about generalisability. The participants' accounts reflect their experiences; of a specific group within a specific context. It is therefore considered that a different group of participants, recruited via different means or analysed by a different researcher would have led to a different understanding of the phenomenon under investigation. Furthermore, it is also important to consider potential selection bias amongst those that chose to participate. The title and aims of this study may have attracted certain participants, for example perhaps those who continue to struggle with their experiences of PTI during adolescence may be more interested in talking about their experiences. As such the experiences of those who chose to participate may have been substantially different from those who did not.

It should also be noted that the researcher is a Counselling Psychologist in training, and whilst Counselling Psychologists are "research-practitioners", tensions may exist in managing and moving between these discrete roles. Working with issues such as grief and loss in a clinical setting requires a different approach and discrete skills to those required as a researcher, who aims to explore participant experiences within a research capacity. As such, there may be unique challenges in keeping these roles distinct throughout the research process which should also be considered as a potential limitation.

It should also be considered that the current study did not make distinctions between types of terminal illness diagnosis. Whilst, the majority of participants' parents had received a terminal cancer diagnosis, one participant had lost a parent to terminal illness, relating to HIV. This participant spoke about additional adjustment and implications associated with the diagnosis which were not able to be fully explored within the current study. However, issues relating to stigma and teasing at school were raised. It may be that illnesses such as

HIV present further complexities and complications, which would benefit from being further explored.

All of the participants in the current study were white British adults and religion and spirituality were not discussed prior to or during interview. However, the cultural and religious background of adolescents may be of significance when considering their response to PTI and death (Robin & Omar, 2014). Traditions, rituals and beliefs surrounding death, burial and ongoing life may be significantly impactful. Furthermore, characteristics of “normative” grieving responses may vary significantly according to cultural and religious background (Balk, 1991; Batten & Oltjenbruns, 1999) and for many adolescents, their religious community may form an integral part of their social support network following bereavement. However, these elements did not form part of the present study.

Participants in the current study were not recruited according to gender, however it should be noted that only one of the participants was male. This participant spoke about the potential role of gender stereotyping, or perceptions of gender stereotyping and he expressed how, as a male, he felt less able to demonstrate emotion and ask for help when he needed it because of his gender. Whilst a number of studies (E.g. Huizinga et al., 2005; Raveis & Siegel, 1999) have suggested that males may experience less distress than females when a parent is unwell, the experiences and perceptions of the male participant in the current study may arguably add credence to the question of whether males may be less likely to show or report distress than their female counterparts. However, as there was only one male participant in the current study, there was limited scope for further or more detailed exploration of these elements; particularly in terms of a greater understanding of any potential additional complexities associated with being male within this context.

A further area of consideration, is that of retrospective accounts. Retrospective accounts are frequently used in both qualitative and quantitative research, as it often proves difficult to capture experiences in the moment that they occur. However, research has previously asserted that individual memories are altered and shaped by many different factors such as; an individual’s life course, social structures, and even patterns of historical events (Schuman, Rieger & Gaidys, 1994); intimating that memories and perceptions alter over time. Contrary research findings however indicate that retrospective accounts do demonstrate a useful degree of accuracy, even demonstrating accurate recall up to 50 years after an event (Berney & Blane, 1997). Whilst the current study imposed a maximum age of 30, to increase homogeneity of the sample and reduce time passed since the event, it may also be the case that individual perceptions have altered significantly over time. Some memories may have been incompletely or inaccurately recalled, and the meaning of experiences presently, may be quite different from the meanings attributed at the time of PTI.

Finally, it is noted that the interviews conducted as part of this research were conducted via telephone. This was based upon research findings suggesting that participants may feel more relaxed and able to disclose sensitive information when the interviewer is not present (Kavanaugh & Ayres, 1998; Opdenakker, 2006). Thus, telephone interviews have been considered particularly useful where traumatic and sensitive topics are being discussed (Trier-Bieniek, 2012). Drabble et al. (2016) similarly argue that telephone interviews offer viability and validity as a method for collecting rich narrative data on sensitive topics and Trier-Bieniek (2012) further asserts that telephone interviews may generate more “honest data” (Trier-Bieniek, 2012, p.630) as people have become more accustomed to virtual communication. However, telephone interviewing may also hold limitations; namely the absence of visual cues and potential difficulties in establishing rapport. Whilst this was not experienced in the present study by the researcher, there were instances of over speaking and over hesitance and it may have been beneficial to witness how participants responded to questions and topics visually. However, the researcher aimed to be particularly attentive to alternative non-visual cues; such as pausing, sighing, tone of voice and emphasis. These elements were transcribed by the researcher and formed part of the data analysis process, and therefore not all non-visual cues were lost as a result of telephone interviewing. It should also be noted that the participants appeared able to talk openly regarding particularly sensitive and emotive elements of their experience, and whilst this may not be entirely owing to telephone interviewing, the researcher experienced this method of data collection as appropriate and constructive within the context of this study.

6.8 Conclusions and future directions

The results of the present study provide evidence to suggest that the six individuals who took part in the study perceive their experiences of PTI during adolescence as forming a central crux in their life-story. Whilst participants highlighted the complexities and difficulties of this period in their lives, for them and their families, they also stressed how their experiences continue to impact their daily lives. Yet, despite apparent difficulties in coping and adjusting both pre-and post-bereavement, participants also intimated how adolescents, in particular, may have a complex relationship with support-seeking; struggling to find supportive others, and also in accessing and making use of available services. As a result, there are several areas for further research that could potentially follow on from the present study.

Firstly, results from the present study suggest that reduced information-sharing and communication patterns in families, may inhibit adolescents' understanding of PTI; leaving them potentially less prepared for later stages of parental illness and bereavement. Miller (2008) similarly suggests that the more information adolescents received regarding their parent's illness, the fewer psychological symptoms they experience, and open communication within families regarding illness has likewise been linked to children's resilience and overall sense of wellbeing (Osborn, 2007; Rainville & Dumont, 2010; Thastum et al., 2008; Wong et al., 2010). Thus, research further exploring information-sharing and communication patterns in families with adolescent children, affected by PTI may be of use. Particularly considering how parents decide which information to provide adolescent children with and how this information is conveyed.

Secondly, results from this study suggest that adolescents' relationship with their surviving parent may be of particular significance, in terms of adjusting to PTI and bereavement. It appeared therefore, that for the participants in this study, the relationship with the surviving parent was a potential risk/protective factor, whereby more distant or conflictual relationships led to less positive coping and adjustment (potentially including the use of drugs and alcohol as a means of coping). It may therefore be worth considering this relationship in a larger-scale study, to establish whether the relationship with the surviving parent holds up as a risk/protective factor for adolescents facing PTI and bereavement.

As a third point, the role of gender might be given further consideration. Whilst there was only one male participant in the present study, he appeared to perceive gender stereotyping as a significant part of his experience of PTI and bereavement; particularly in relation to asking for help and showing emotion. This also appears to be an underdeveloped area of the literature, and future research could potentially consider the role that gender, and perceptions of gender might play for adolescents. For example, exploring how concepts of masculinity or social constructions of gender might impact expressions of grief and loss for adolescent males.

U.K. bereavement services are diverse in terms of their location, service offerings, organization, waiting times, funding and the interventions offered (Rolls & Payne, 2004). These differences make it hard to present a clear picture of bereavement services and for researchers to compare and evaluate. Future research might therefore consider ways to improve and increase evaluation of childhood bereavement services and pre-bereavement care. Furthermore, Rolls & Payne (2004) stress the importance of the experiences of service users in understanding, improving and designing effective services and interventions for bereaved children, however findings from the current study also suggest that the perceptions of non-service-users may also be useful in understanding why adolescents may be reluctant to access services and how accessibility and engagement may be improved. In addition, results from this study suggest that social acceptability and stigma may inhibit adolescent support-seeking and these factors may also be usefully explored through further research.

Future research may also focus on finding a suitable working model of grief and loss for adolescents. As addressed in the critical literature review chapter, the most prominent theories and models of grief and loss, have been conceived primarily in relation to adult experience, and there are few that focus on young people's experiences of grief and loss from their own perspective (Rolls & Payne, 2007). Yet, findings from existing research and the present study suggest that PTI and bereavement during adolescence, may present a distinctly challenging and complex experience. It could therefore be argued that a model or theory that aligns with and represents adolescent experiences may be of benefit to both healthcare professionals and adolescents.

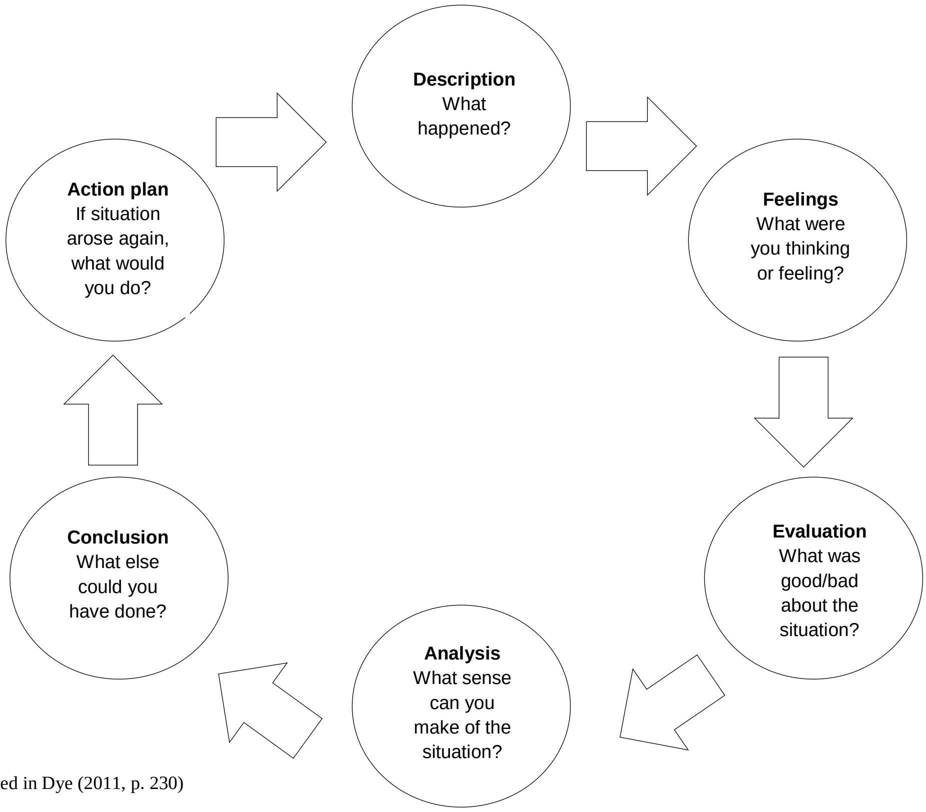
Sheehan et al. (2014) suggest that adolescents with divorced parents may have different communication styles which may be an area of future research. The current study similarly suggests that parental divorce may add a different dynamic to parental terminal illness and bereavement, particularly if the unwell parent is viewed as the primary caregiver, or where parental relationships are challenging or conflictual. Future research might therefore consider how factors such as parental separation or divorce might influence adolescent experiences of PTI and bereavement.

Finally, Elaine Kasket's (2012) paper on "Being-Towards-Death in The Digital Age" highlights the pertinent role that social-networking sites have begun to play in grief processes. From finding out about someone's death, to public displays of grieving or ongoing relationships with the deceased. Kasket (2012) suggests that due to the prevalence of social-media, death and in fact the deceased may pose an increasing presence in people's lives. Grieve, Indian, Witteveen, Tolan and Marrington (2013) similarly suggest that social networking sites such as Facebook, may provide an alternative social outlet, which may be associated with a range of positive psychological outcomes. This may be an important factor for adolescents, who are primary users of the internet and social-networking sites. Due to the retrospective nature of the current study, participants were not adolescents during the time of prominent sites such as Facebook, Twitter and Instagram and therefore this element did not form part of the current study. However, the role of social media in adolescent's grieving processes may be an area of special interest; particularly in whether it provides a useful outlet for expressing grief reactions and whether it serves to degrade any stigma or mystery surrounding bereavement. There may also be scope for exploring the potential impacts of cyber-bullying and internet trolling in relation to adolescent expressions of grief.

6.9 Concluding reflections

An awareness of subjectivity is central to counselling psychology (Orlans & van Scoyoc, 2008). It denotes the way in which our experiences, beliefs, values and contexts impact our perspectives. As such, I have maintained an awareness of my assumptions and their impact on my research throughout this project. However, as expressed in my opening reflexive statement, this has been a new and challenging experience. What has helped, is continued engagement in reflexive activities, such as keeping a reflective journal (appendix B), participating in reflexive research groups and utilizing supervision. Gibbs (1988) reflective cycle (Figure 1) has also helped bring structure and continuity to my reflective practices; encouraging open reflection and engagement throughout the research process and ensuring that challenges have been translated into learnings.

Figure 1.0 Gibbs' (1988) reflective cycle



*As cited in Dye (2011, p. 230)

I entered into this research project contemplating how older adolescents might experience and respond to parental terminal illness. Considering whether their experiences might differ from those of adults and even children? Whether factors associated with their developmental stage might come in to play? And where they may turn to for support?

My initial perception entering into this project was that parental terminal illness during adolescence may be uniquely challenging; as the changes and transitions associated with this developmental stage are combatted alongside the complex stressors placed on adolescents and their families by PTI and bereavement. Personally, I also wished to consider what might be useful and constructive to these individuals. Hoping, in many ways, to find elements of adjustment and growth following adversity. At the beginning of the research process this appeared difficult; as much of the literature consisted of poor adjustment and psychosocial outcomes following parental illness and death during adolescence. I particularly recall writing in my reflexive diary about how for those with personal experience of parental terminal illness during adolescence, the literature may appear discouraging and dispiriting.

Conducting the interviews which made up this research project, demonstrated for me, how the individuals' experiences had impacted and continued to impact their lives. Their stories were laden with emotion which was challenging to witness. I felt extremely privileged that the participants had elected to share their personal experiences with me, and I felt a great responsibility in doing their accounts justice. Also, I was deeply moved by the individual's determination to take or make something positive grow from their experiences. Whether this be attempting to live life to the full, and truly appreciate those nearest and dearest. Or help and support others through times of difficulty, by working in a caring profession or volunteering and fundraising. On both a personal and professional level, I found myself wanting to be able to offer the participants guidance, support and comfort. Contemplating this desire to help, made me acknowledge the closeness I felt to the participants; perhaps in some ways through my own experiences of close bereavement. This has also made me question whether what drew me to wanting to become a psychologist, has similarly drawn the participants to caring professions and vocations.

Conducting this research has given me an insight into how parental terminal illness and death can be experienced during adolescence and particularly how far-reaching its impacts may be. The variability in responses and adjustment reflects the personal and individualistic nature of grief and loss, which has prominently filtered through in to my work with those grieving. Equally, the strength and determination of my participants to draw some positive from negative has deeply resonated with me personally and professionally.

7.0 References

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8.0 Appendices

Appendix A

Literature search strategy

The papers obtained and presented within the current study were accessed via online databases such as PsychINFO, PsychArticles, and EBSCOhost. A wide variety of search terms were used independently and in differing combinations. Search terms included; “terminal illness”, “parental terminal illness”, “bereavement”, “palliative care”, “adolescence”, “older adolescence”, “young people”, “children”, “loss”, “death”, “Anticipatory Grief”, “grief”, “mourning” and “chronic illness”. Utilizing the reference sections of the papers found, further assisted in identifying other relevant papers (i.e. adopting a “snowballing” technique).

Specific journals such as; “Journal of Death and Dying”, “Journal of Palliative Care”, “The Family Journal”, “Clinical Psychology Review”, “Counselling Psychology Quarterly”, and “The Counseling Psychologist”, were also searched as potentially providing relevant content for the current study. Approximately 200 journal articles were read, alongside numerous books, book chapters and article abstracts. Additional searches were also conducted for relevant books and journals in the London Metropolitan University library.

Appendix B

Organisations contacted during recruitment phase

- Association of Bereavement Service Coordinators: hospice and palliative care (ABSCo)
- Cancer Research UK
- Child Bereavement Network
- Child Bereavement UK
- Chums
- Cruse Bereavement Care
- Eden Hall
- Grief Encounter
- Holding On Letting Go
- Just “B” Bereavement Support
- Macmillan Cancer Support
- Marie Curie Hospice
- Mind
- Mosaic Family Support
- North London Hospice
- Simon Says
- St.Anne’s Hospice
- St Christopher’s Hospice
- St John’s Hospice
- Trinity Hospice
- University of Sheffield
- Winston’s Wish

Appendix C

Email sent to organisations contacted during recruitment phase

Email subject: Doctoral Research Study exploring 16 -18-year-old adolescents' experiences and responses to parental terminal illness

Email text:

To whom it may concern,

My name is Jennifer Cafferky, and I am currently studying for a Professional Doctorate in Counselling Psychology at London Metropolitan University. For my doctoral thesis, I am undertaking a research project concerned with adolescent's experiences and responses to parental terminal illness.

My research project involves speaking with individuals who may have had a terminally ill parent whilst they were aged between 16 and 18 years old. There is an apparent lack of literature focusing on how older adolescents experience parental terminal illness and death. My research has a particular focus on adolescent's experiences and responses during the time of their parent's illness and post bereavement. This research project aims to add to the literature gap in this area; gaining insight into how adolescents experience and respond to parental terminal illness and the particular challenges they may face and thus how they might best be supported.

I am hoping to recruit individuals aged under 30 years old who had a parent receive a formal diagnosis of a terminal illness whilst aged between 16 and 18 years. Individuals who wish to take part, would be required to take part in a telephone interview lasting approximately 60 minutes. All information will be anonymised and any identifying details redacted.

I am presently contacting organisations, who may be able to assist with my recruitment process, whether by helping me gain access to my required population group or by displaying/disseminating my research recruitment poster and information sheet. Any help that you are able to provide would be greatly appreciated.

Many Thanks,

Jennifer Cafferky

Email: jec0322@my.londonmet.ac.uk / Tel: 07932451895

Appendix D

Recruitment poster

LONDON
metropolitan
university

Volunteers required for a research study exploring adolescents' experiences of parental terminal illness

I am a trainee Counselling Psychologist and I am conducting a research study as part of my professional doctorate training programme that aims to retrospectively explore the experiences of older adolescents with a terminally ill parent.

Adolescents are underrepresented in bereavement research and little is known about the challenges faced by adolescents when a parent is diagnosed with a terminal illness. Your involvement in this research study would help to gain a better understanding of how adolescents experience having a terminally ill parent, in order to further support adolescents.

Your involvement would require a one-hour telephone interview at a time convenient for you. Your anonymity and confidentiality will be maintained throughout the study.

You are invited to take part in this research project if you had a parent receive a terminal illness diagnosis whilst you were aged between 16 and 18 and you are now aged 30 or below.

Many thanks for taking the time to read this information.

Jennifer Cafferky
Email: jec0377@my.londonmet.ac.uk
Tel: 07932451895

This research study has been approved by the London Metropolitan University Research Ethics

Appendix E

Information Sheet

Study Title: A retrospective study exploring how 16 -18-year-old adolescents experience and respond to parental terminal illness: An Interpretative Phenomenological Analysis

Researcher: Jennifer Cafferky

Invitation: You are being invited to take part in the above titled research project which is being carried out by myself, Jennifer Cafferky as part of my Professional Doctorate in Counselling Psychology. Before you decide whether or not you wish to take part, it is important to understand why this research is being done and what it will involve. Please take time to read this information clearly and discuss it with friends and family if you wish before deciding to take part. Please ask if there is anything that is unclear or if you would like more information.

Why am I being asked to take part?

You are invited to take part in this research project if you had a parent receive a terminal illness diagnosis whilst you were aged between 16 and 18 and you are now aged 30 or below. You are therefore invited to participate in this study as you have experiences of parental terminal illness and this research project aims to add to the knowledge in this area.

Do I have to take part?

You do not have to take part in this study and it is your choice if you wish to participate. If you do decide to participate in the study and then change your mind for any reason, you will be able to withdraw from the study any time before, during or up to one month after interview (as the data will have begun to be analysed at this time). You do not need to provide a reason for withdrawing from the study.

What will happen if I take part?

If you decide to take part in the study, I will contact you to arrange an interview (as detailed below) and I will provide you with a consent form to read carefully. You will then be asked to complete a copy of the consent form prior to beginning the interview.

If I take part, what do I have to do?

If you decide to take part in this study, you will be asked to participate in an interview to discuss your experiences of parental terminal illness. Interviews will be conducted via telephone and arranged at a time to suit you. The interview itself should take approximately one hour. The interview will be audio-recorded with your consent.

What are the benefits (if any) of taking part?

Little research has so far focused on the experiences of older adolescents with a terminally ill parent, particularly in terms of their experiences of coping, their family relationships and their responses both pre and post bereavement. This study is also interested in perceptions and experiences of available support. This study thus aims to add to literature in this area, inform further research and potentially aide professionals who work with this client group.

What are the risks (if any) of taking part?

The topic being researched is of a personal and sensitive nature and therefore it is possible that discussing the topic may cause emotional upset. However, the interview questions have been developed in order to minimise such upset and the London Metropolitan University Distress Protocol will be followed in the event that any distress is caused. You will also be provided with contact details for various organisations if you feel that you would benefit from accessing support services following the interview.

Who will have access to information about me?

All of the information you provide will be stored safely on a password protected database to which only the researcher will have access. All of the information gathered will be stored anonymously and pseudonyms will be assigned in order to protect your anonymity in the thesis and any subsequent publications. All data collected will be stored and safely disposed of in line with London Metropolitan University's Thesis Guidelines.

Who is funding and organising the research?

This research is being conducted as part of a Professional Doctorate in Counselling Psychology and therefore no funding has been received towards the carrying out of this research. The research is being carried out by myself and will be supervised by Dr Samantha Banbury who is a lecturer at London Metropolitan University.

What if there is a problem?

To reduce the risk of distress being caused it is asked that anyone interested in participating in this research project has not been recently informed that they have a mental health condition such as anxiety or depression. Due to the sensitive nature of this topic, you may feel that it would be too upsetting to talk about your experiences and therefore I would like to thank you for taking an interest in this study but suggest that you do not take part.

If there is any problem during the interview, we can stop the interview process and we can discuss possible next steps such as sources of support which may be useful for you. We will not continue the interview unless you feel happy and able to do so. If there are any further concerns, please feel free to contact me and additionally my supervisor whose contact details will also be provided.

I look forward to hearing from you.

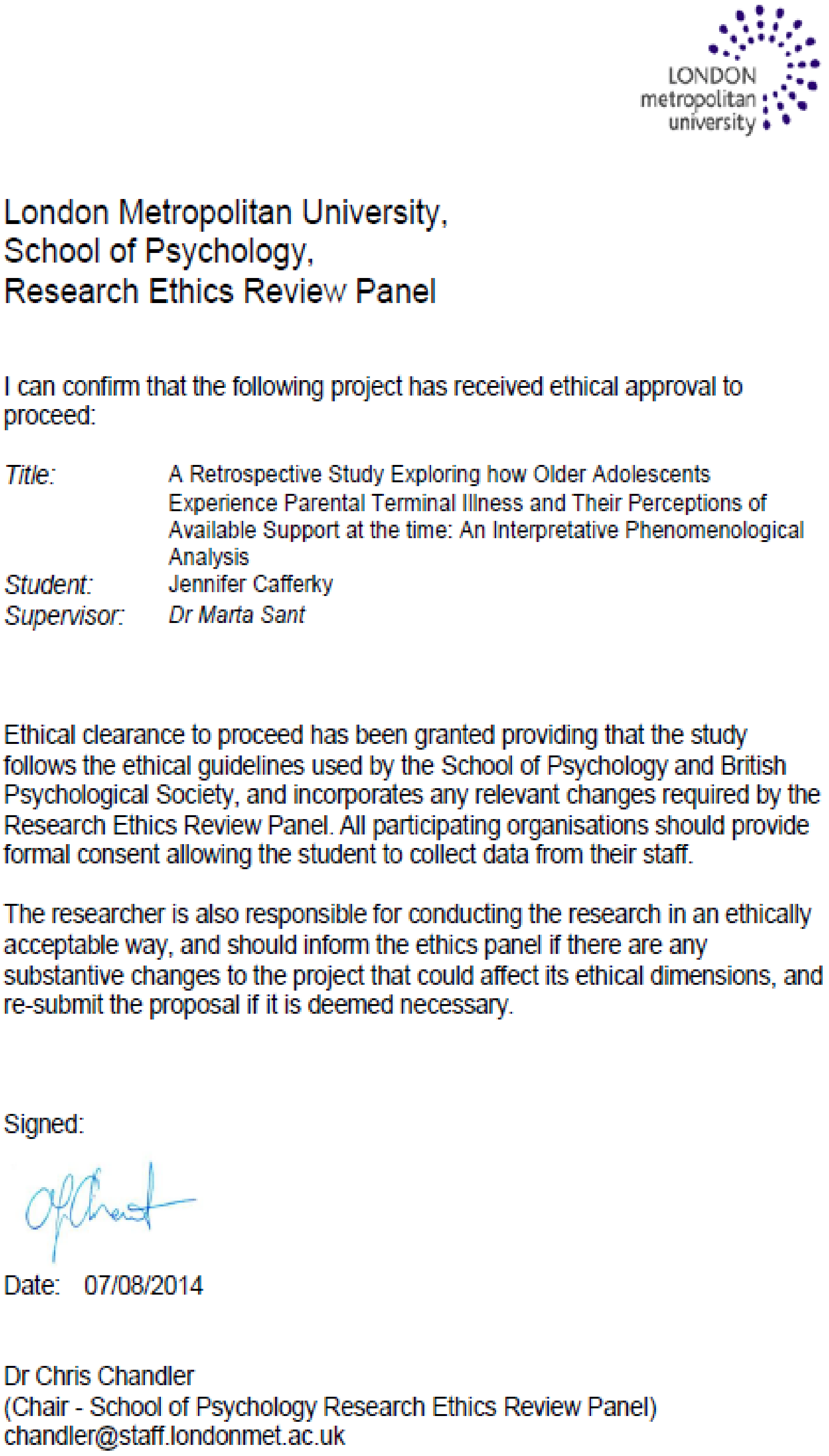
Kind regards,

Jennifer Cafferky
Trainee Counselling Psychologist
Email: jec0377@my.londonmet.ac.uk
Tel: 07932451895

Supervisor
London Metropolitan University
Dr. Samantha Banbury
Email: s.banbury@londonmet.ac.uk

Appendix F

Ethical consent certificate



London Metropolitan University,
School of Psychology,
Research Ethics Review Panel

I can confirm that the following project has received ethical approval to proceed:

Title: A Retrospective Study Exploring how Older Adolescents Experience Parental Terminal Illness and Their Perceptions of Available Support at the time: An Interpretative Phenomenological Analysis
Student: Jennifer Cafferky
Supervisor: *Dr Marta Sant*

Ethical clearance to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed:

Date: 07/08/2014

Dr Chris Chandler
(Chair - School of Psychology Research Ethics Review Panel)
chandler@staff.londonmet.ac.uk

Appendix G

Participant consent form

Dear participant,

Thank you for taking the time to be a part of this study. Please read the following statements and if you agree, sign your consent at the bottom of the page. By signing this form, you agree to the below statements and are consenting to take part in this study.

1. I understand that my participation is voluntary.
2. I am aware of what my participation will involve and have read the information sheet provided.
3. I understand that I am free to withdraw at any time before or during the study without question. However, if I wish to withdraw my consent post interview it has to be done within one month from the date of interview. No reason from withdrawing need be given.
4. I understand that my name will not be used in connection with the results in any way and that I will be given a pseudonym. All information that may otherwise identify me (e.g. address, friend's names) will be changed prior to transcription.
5. I understand that confidentiality will however be breached if any information is disclosed prior to, during or after the interview that indicates a risk to the safety of the participant or any other person.
6. I understand that the results of the study will be accessible to others when completed and that excerpts from my interview (minus identifying information) will be used within the study. I also understand that the findings of this study may be published.
7. I understand that audio recordings and other data form (e.g. consent forms) will be stored securely and that the data will be destroyed after this study has been examined.
8. I understand that I may find this interview upsetting and that it may evoke a number of difficult and distressing feelings for me. I will be offered support and the opportunity to discuss these feelings at length post interview with the researcher. The researcher will also give information on further support available if required.
9. I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be given in the debriefing form.
10. I understand that the data will be destroyed in accordance with London Metropolitan University Thesis Guidelines.
11. All questions that I have about the research have been satisfactorily answered.

I agree to participate.

Participant's signature: ________________________________

Participant's name (please print): ________________________________

Tick this box if you would like to receive a summary of the results by e-mail ☐

E-mail: ________________________________

Date: __________

Contact Details

Jennifer Cafferky
Trainee Counselling Psychologist
Email: jec0377@my.londonmet.ac.uk
Tel: 07932451895

Supervisor
London Metropolitan University
Dr. Samantha Banbury
Email: s.banbury@londonmet.ac.uk

Appendix H

Distress protocol

Protocol to follow if participants become distressed during participation:

This protocol has been devised to deal with the possibility that some participants may become distressed and/or upset during their involvement in this research, given the personal and sensitive nature of the topic.

It is not expected that severe distress will occur, nor that the relevant action will become necessary. However, it is included in the protocol, as with all points to enable the researcher to identify, and minimise any potential distress or anxiety experienced by a participant as a result of the research process.

The below distress protocol has been constructed based on the recommendations of Draucker, Martsolf and Poole (2009) on the development of distress protocols for research concerning sensitive subjects.

Table 3.0 Distress protocol

Distress level	*Indicators to be aware of*	*Action to take*
Mild	▪ Tearfulness ▪ Voice becomes choked with emotion/ difficulty speaking ▪ Participant becomes distracted/ restless	▪ Ask participant if they feel OK to continue ▪ Offer the participant time to pause the interview and compose themselves ▪ Remind them they can stop at any time they wish to
Severe	▪ Uncontrolled crying, inability to talk coherently ▪ Panic attack- e.g. hyperventilation/shaking ▪ Intrusive thoughts of the traumatic event - e.g. flashbacks	▪ The researcher will stop the interview ▪ The debrief will commence immediately ▪ Express concern, empathy and ▪ reassurance that reactions ▪ are normal ▪ Suggest relaxation techniques to calm and regulate breathing ▪ Accept and validate participant distress and suggest they contact their healthcare provider ▪ Provide details of support services and organisations which can be contacted following the interview

Appendix I

Debriefing sheet

Dear Participant,

Thank you for taking part in my research project. This study forms part of my Professional Doctorate in Counselling Psychology at London Metropolitan University. If you are interested in the results of this study, if you have any questions about this study, or if you wish to withdraw, please contact me on the following email address: jec0377@my.londonmet.ac.uk or via telephone: 07932451895.

It is the purpose of this research project to gain a clearer understanding of how older adolescents' experience and respond to parental terminal illness through retrospective accounts. Little research has so far focused on the experiences of older adolescents with a terminally ill parent, particularly in terms of their experiences of coping, their family relationships and their responses both pre and post bereavement. Your contribution to this study is extremely valuable and will help add to existing knowledge in this area, inform further research and potentially aide professionals who work with this client group.

Please remember you are free to withdraw from the study up until one month prior to your interview date, as it may not be possible at a later stage. Also, if you have any questions or concerns regarding the research project, please do not hesitate to contact me in the first instance or my research supervisor Dr Samantha Banbury on: (s.banbury@londonmet.ac.uk).

If your participation in this study has led to any further concerns or issues that you wish to discuss further there are a number of organisations who can provide confidential advice and support and the contact sheet for sources of support will be provided to you.

Many thanks again for participating in my research project,

Jennifer Cafferky

Appendix J

Sources of support: contact sheet

If you feel that as a result of participating in this study you are experiencing any difficult emotions that you would like support for, a list of services you may wish to contact is provided below.

The Samaritans.
The Samaritans provide free confidential 24-hour support over the phone. They listen, help you talk through your concerns, worries and troubles.
Website: http://www.samaritans.org/
Tel: 08457 90 90 90

Cruse Bereavement Care
Cruse Bereavement Care is the leading national charity for bereaved people in England, Wales and Northern Ireland. We offer support, advice and information to children, young people and adults who have experienced a bereavement.
Website: http://www.cruse.org.uk
Email: helpline@cruse.org.uk
Tel: 0844 477 9400

Macmillan
Macmillan provide support for those whose lives have been impacted by Cancer.
Website: http://www.macmillan.org.uk/HowWeCanHelp/TalkToUs/Talktous
Website: www.macmillan.org.uk/community
Tel: 0808 808 00 00 (Monday to Friday, 9am–8pm)

NHS Direct (24-hour service)
111 is the NHS non-emergency number. It’s fast, easy and free. Call 111 and speak to a highly trained adviser, supported by healthcare professionals for medical questions and healthcare advice.
Tel: 111

The British Psychological Society (BPS)
The BPS provides a directory of chartered psychologists. On the BPS website, click on the ‘Psychology & the public’ tab and follow the link to ‘find a therapist’.
Website: www.bps.org.uk
Tel: 0116 254 9568

You can also talk to your GP about other services on offer such as counselling and local support groups.

In an emergency, always call the police on 999.

Appendix K

Interview schedule

Demographic Questions
Gender __________Date of birth ________ (MM/YY) Nationality _________________
How old were you when your parent received their terminal diagnosis? ______________
Was it your mother or father who was unwell? __________________________________

IPA Interview Schedule
Thank you for agreeing to participate in this research study. Before we proceed do you have any questions for me, or is there anything you would like me to go over before we begin?____
I'd like to start by asking you if you could just tell me a little about your reasons for taking part in this study? ____

Initial Open-Ended Questions
Thank you very much for sharing that with me. As you know I am interested in finding out about 16-18 year olds experiences of having a terminally ill parent. Would it be possible to tell me about your experience of your parent's illness? __________________

Ok, so that's given me a really good understanding of your experiences. What I'd like to do now is find out more about what your relationship with your parent was like. How would you describe your relationship to your parent at that time? ___________________

Thank you that has helped me to better understand your relationship with your parent. Would it be possible for you to tell me a bit about your other family relationships at that time? ____

Intermediate Questions
So far we have talked about your experiences of having a terminally ill parent. I would be interested now in talking about how your experiences impacted you. Could you tell me about how you coped during your parent's illness? _______________________________

Thank you very much for sharing that with me. I'd now like to ask you; who or what was helpful to you during that time? ____

As you know I am also interested in your views of professional support services. Are you aware of any support services that might have been available to you at that time? ______
Prompt: Were any made available to you? ______________________________________
Prompt: What do you think about support services available to you during that time? ___

During this interview we have talked about your experiences of having a terminally ill parent and your experiences and perceptions of available support at the time. Do you think that your perceptions and how you view these experiences have changed over time? ____
Prompt: In what way have these changed? _____________________________________

Ending Questions
We're just coming towards the end of the interview. Before we finish I just wanted to ask you if there anything else that you feel it might be important to talk about during this interview? ____
Prompt: What has it been like for you to speak to me today and be involved in this research? ____
Is there anything you would like to ask me? ____________________________________

Appendix L

Reflexive diary extracts

22/04/2014

It is interesting reading the literature regarding young peoples' experiences of parental illness or death. The majority of papers focus solely on the potential negative impacts of experiences. I wonder whether there is another side to this that has received less attention. Studies describe young people being more involved in care and domestic tasks; could this be a form of change/maturity/growth for some individuals?

12/03/2015

Talking about my research with other people has started my thinking with regards to family dynamics. Each family is unique and may therefore have unique challenges. For example, might it be different for an adolescent to experience parental terminal illness if they already have a deceased/absent/distant parent? Could this serve as a further "bereavement" whereby the adolescent is in a way "orphaned"? It would be interesting for further research to look in more detail at the family structure prior to diagnosis.

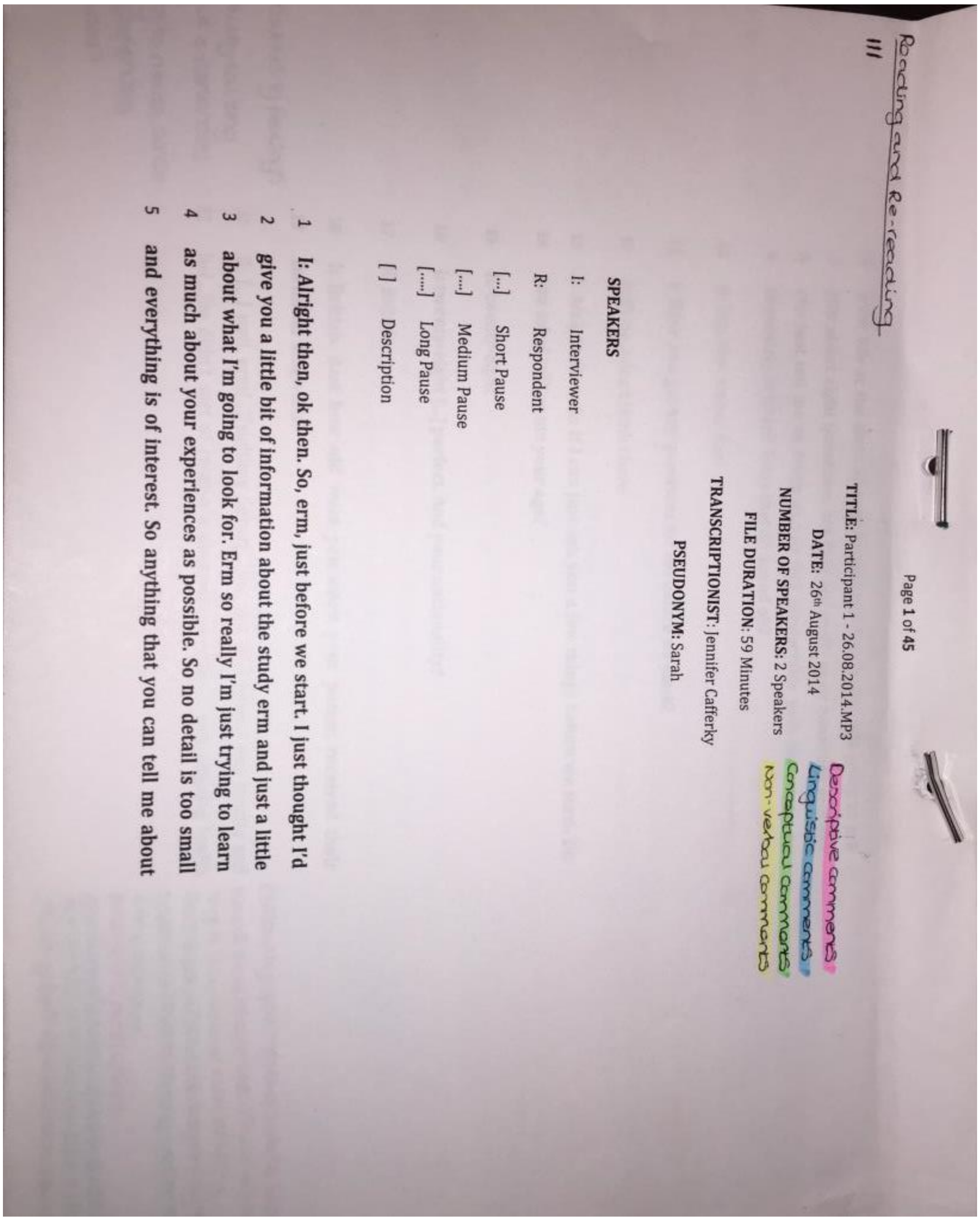
03/08/2016

I have been finding it challenging to keep the study focused, as there appear to be so many different aspects to explore and discuss. The adolescent – their social, developmental and cultural context. The family – system, structure and relationships. Support – family, friends, peers and services. There are also so many other elements to consider. Does the internet/ social media play a part in adolescents' experiences of PTI and bereavement? Some areas will need to be outlined as considerations for future research. However, this has led me to reflect on whether my sense of being overwhelmed somehow mirrors the participants' sense of being inundated and overwhelmed?

Appendix M

Transcript Example

Figure 1. Examples from the annotated transcript for participant 1, displaying the initial development of emergent themes[1].



Reading and Re-reading

III

Page **1** of **45**

TITLE: Participant 1 - 26.08.2014.MP3

DATE: 26th August 2014

NUMBER OF SPEAKERS: 2 Speakers

FILE DURATION: 59 Minutes

TRANSCRIPTIONIST: Jennifer Cafferky

PSEUDONYM: Sarah

Descriptive comments
Linguistic comments
Conceptual comments
Non-verbal comments

SPEAKERS

I:	Interviewer
R:	Respondent
[...]	Short Pause
[....]	Medium Pause
[.....]	Long Pause
[ ]	Description

I: Alright then, ok then. So, erm, just before we start. I just thought I'd give you a little bit of information about the study erm and just a little about what I'm going to look for. Erm so really I'm just trying to learn as much about your experiences as possible. So no detail is too small and everything is of interest. So anything that you can tell me about

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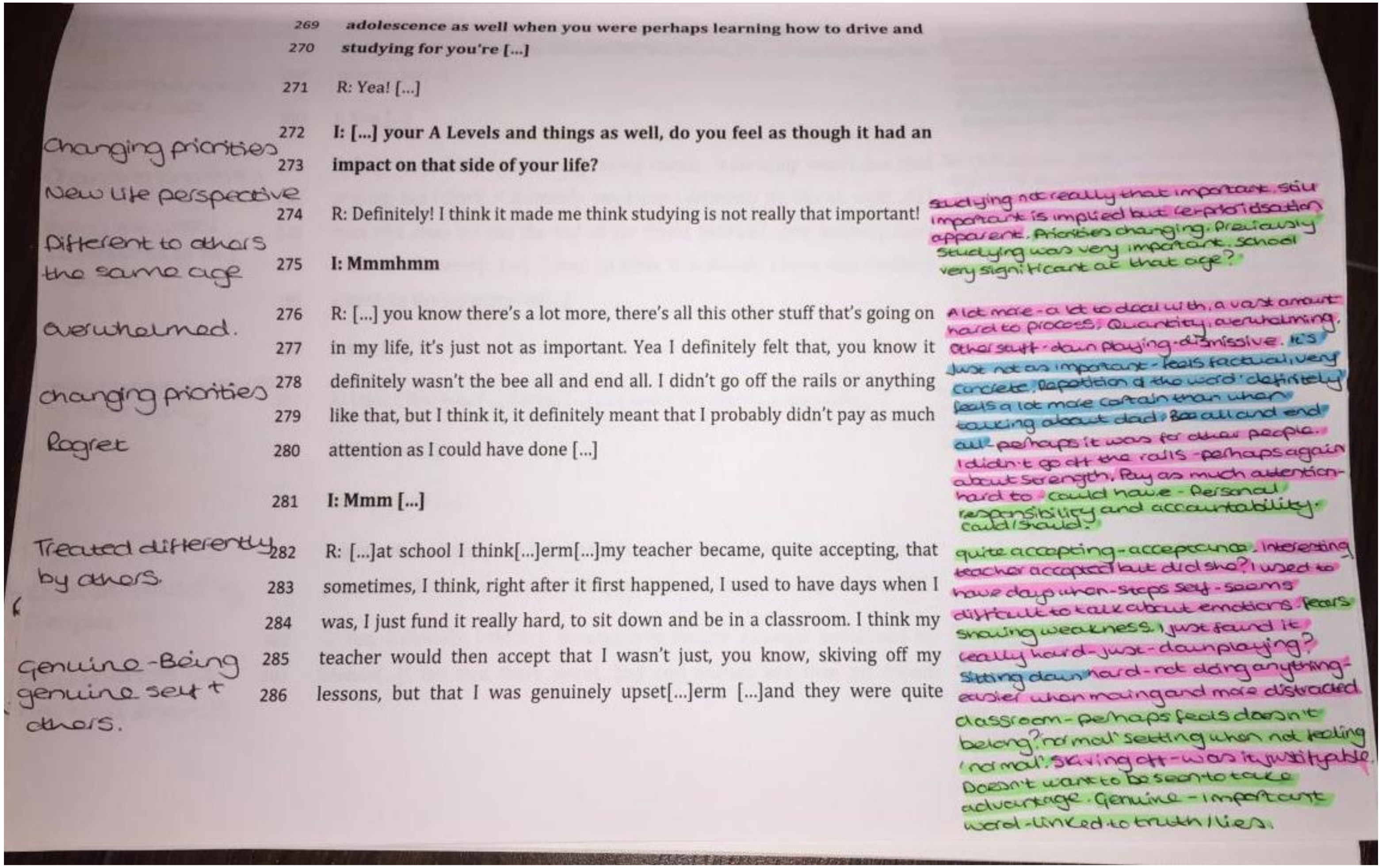
[1] Exploratory comments were noted on the right-hand side of the page, followed by emergent themes on the left-hand side.



adolescence as well when you were perhaps learning how to drive and studying for you're [...]

R: Yea! [...]

I: [...] your A Levels and things as well, do you feel as though it had an impact on that side of your life?

Changing priorities

New life perspective

R: Definitely! I think it made me think studying is not really that important!

studying not really that important. still important is implied but re-prioritisation apparent. Priorities changing. Previously studying was very important. school very significant at that age?

Different to others the same age

I: Mmmhmm

overwhelmed.

changing priorities

Regret

R: [...] you know there's a lot more, there's all this other stuff that's going on in my life, it's just not as important. Yea I definitely felt that, you know it definitely wasn't the bee all and end all. I didn't go off the rails or anything like that, but I think it, it definitely meant that I probably didn't pay as much attention as I could have done [...]

A lot more - a lot to deal with, a vast amount hard to process. Quantity, overwhelming. other stuff - down playing - dismissive. It's just not as important - feels factual, very concrete. Repetition of the word 'definitely' feels a lot more certain than when talking about dad. Bee all and end all - perhaps it was for other people. I didn't go off the rails - perhaps again about strength. Pay as much attention - hard to. could have - Personal responsibility and accountability. could/should?

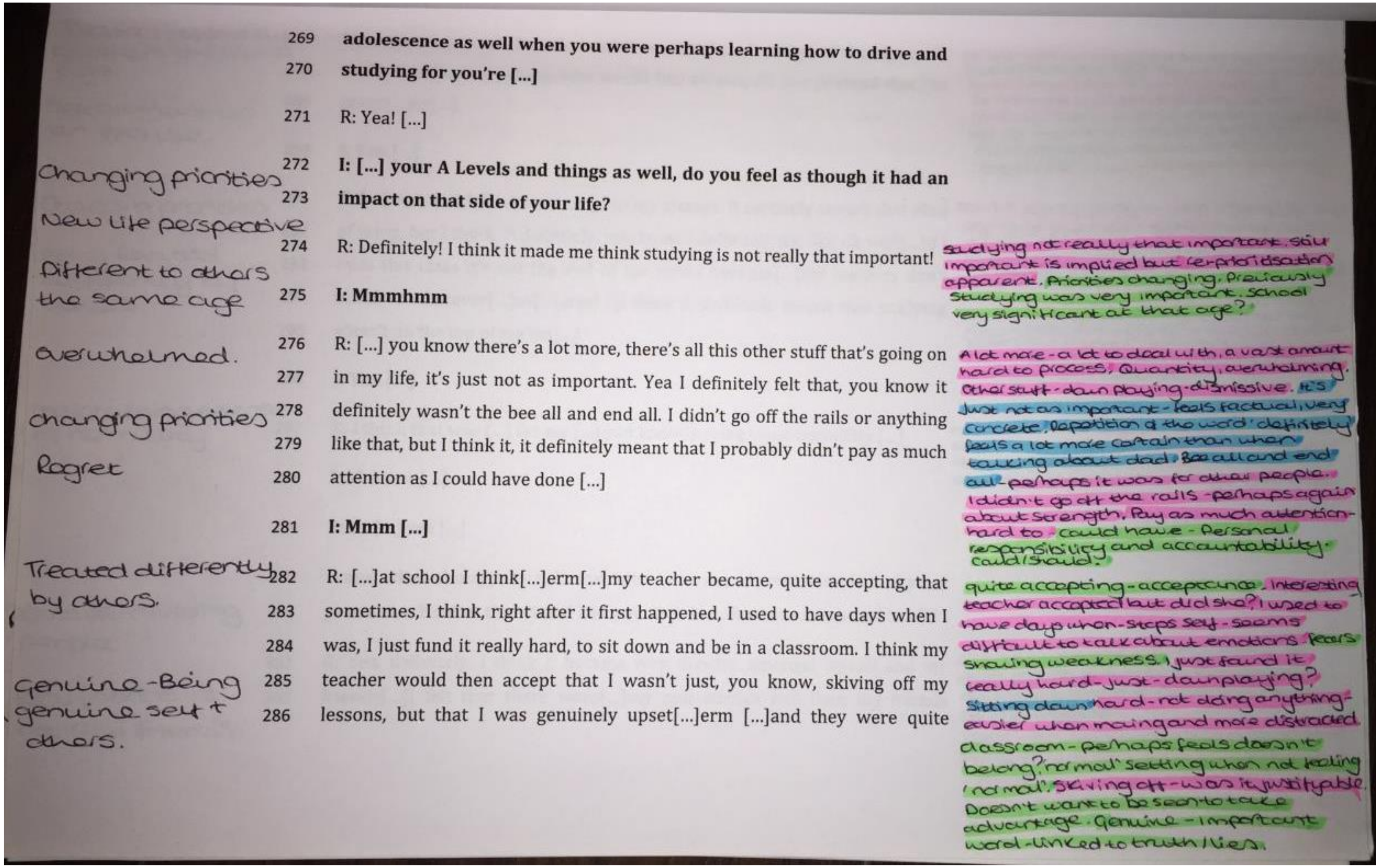
I: Mmm [...]

Treated differently by others.

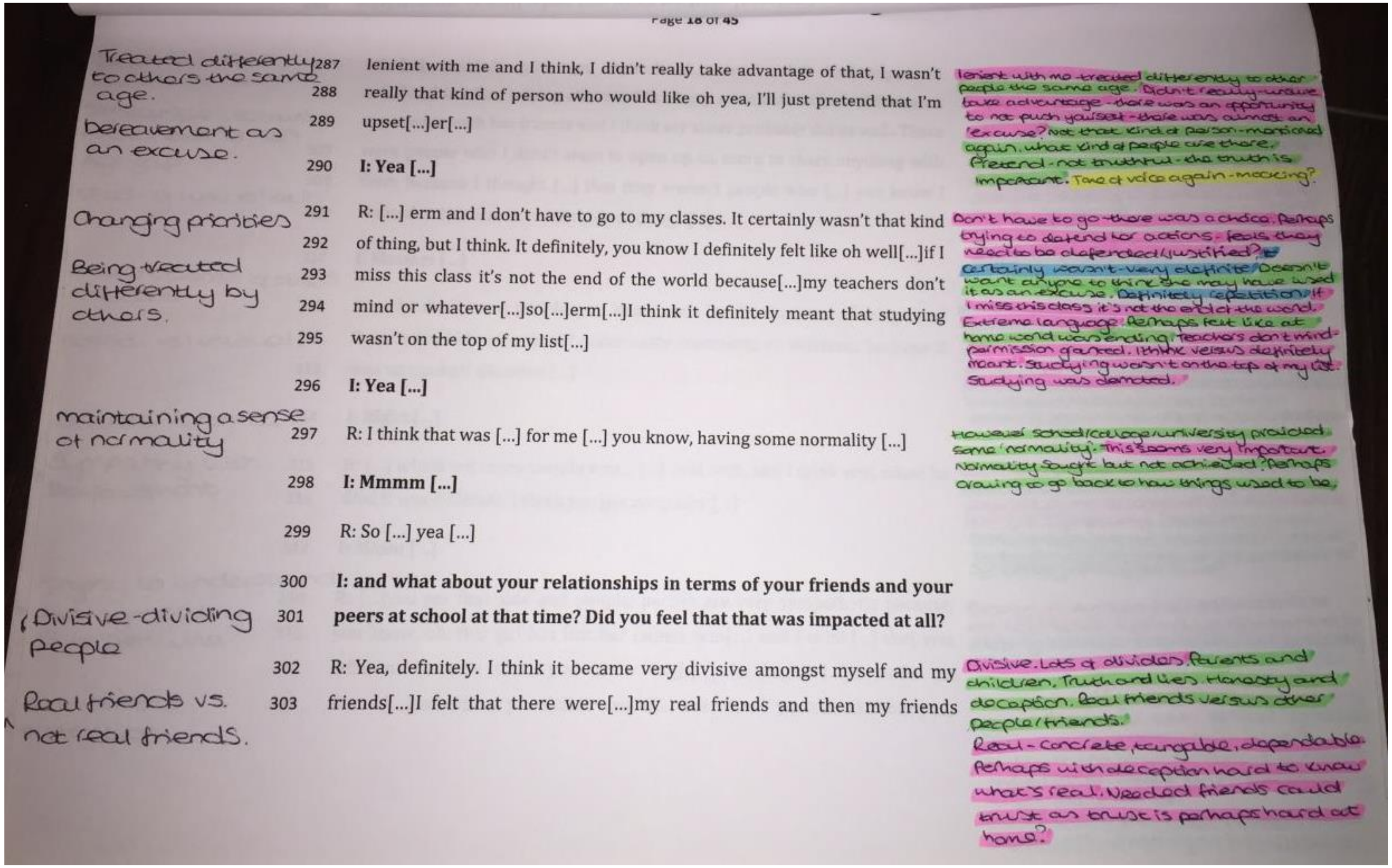
Genuine - Being genuine self + others.

R: [...]at school I think[...]erm[...]my teacher became, quite accepting, that sometimes, I think, right after it first happened, I used to have days when I was, I just fund it really hard, to sit down and be in a classroom. I think my teacher would then accept that I wasn't just, you know, skiving off my lessons, but that I was genuinely upset[...]erm [...]and they were quite

quite accepting - acceptance. Interesting - teacher accepted but did she? I used to have days when - stops self - seems difficult to talk about emotions. fears showing weakness. I just found it really hard - just - downplaying? Sitting down hard - not doing anything - easier when moving and more distracted classroom - perhaps feels doesn't belong? 'normal' setting when not feeling 'normal'. Skiving off - was it justifiable. Doesn't want to be seen to take advantage. Genuine - important word - linked to truth/lies.



	adolescence as well when you were perhaps learning how to drive and studying for you're [...]	
	R: Yea! [...]	
Changing priorities New life perspective	**I: [...] your A Levels and things as well, do you feel as though it had an impact on that side of your life?**	
Different to others the same age	R: Definitely! I think it made me think studying is not really that important!	studying not really that important. still important is implied but re-prioritisation apparent. Priorities changing. Previously studying was very important. School very significant at that age?
	I: Mmmhmm	
overwhelmed. changing priorities Regret	R: [...] you know there's a lot more, there's all this other stuff that's going on in my life, it's just not as important. Yea I definitely felt that, you know it definitely wasn't the bee all and end all. I didn't go off the rails or anything like that, but I think it, it definitely meant that I probably didn't pay as much attention as I could have done [...]	A lot more - a lot to deal with, a vast amount hard to process, Quantity, overwhelming. Other stuff - down playing - dismissive. It's just not as important - feels factual, very concrete, Repetition of the word 'definitely' feels a lot more certain than when talking about dad. Bee all and end all - perhaps it was for other people. I didn't go off the rails - perhaps again about strength. Pay as much attention - hard to - could have - Personal responsibility and accountability. could/should?
	I: Mmm [...]	
Treated differently by others. Genuine - Being genuine self + others.	R: [...]at school I think[...]erm[...]my teacher became, quite accepting, that sometimes, I think, right after it first happened, I used to have days when I was, I just fund it really hard, to sit down and be in a classroom. I think my teacher would then accept that I wasn't just, you know, skiving off my lessons, but that I was genuinely upset[...]erm [...]and they were quite	quite accepting - acceptance. Interesting teacher accepted but did she? I used to have days when - stops self - seems difficult to talk about emotions. fears showing weakness. I just found it really hard - just - downplaying? Sitting down hard - not doing anything - easier when moving and more distracted classroom - perhaps feels doesn't belong? 'normal' setting when not feeling 'normal'. Skiving off - was it justifiable. Doesn't want to be seen to take advantage. Genuine - important word - linked to truth/lies.



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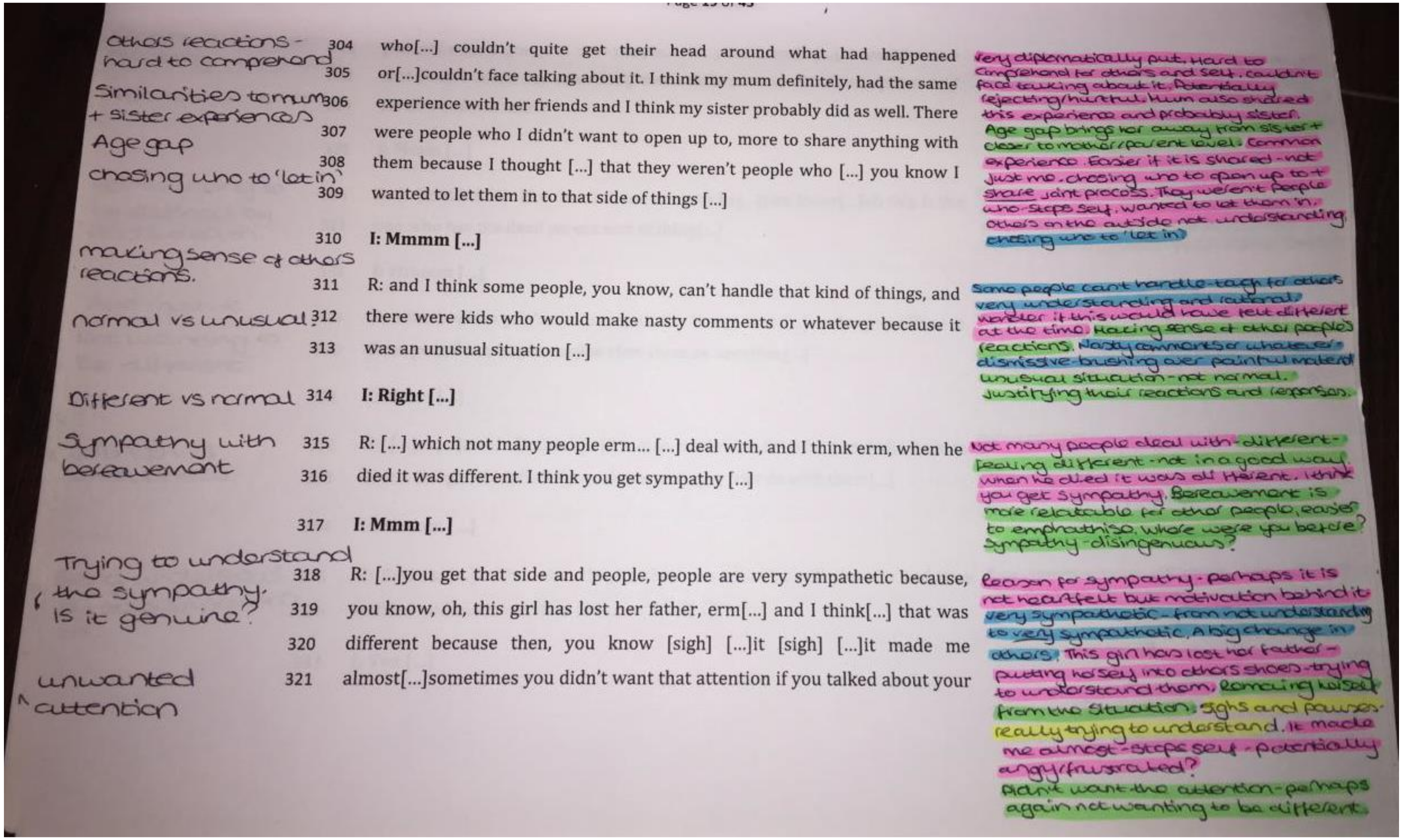
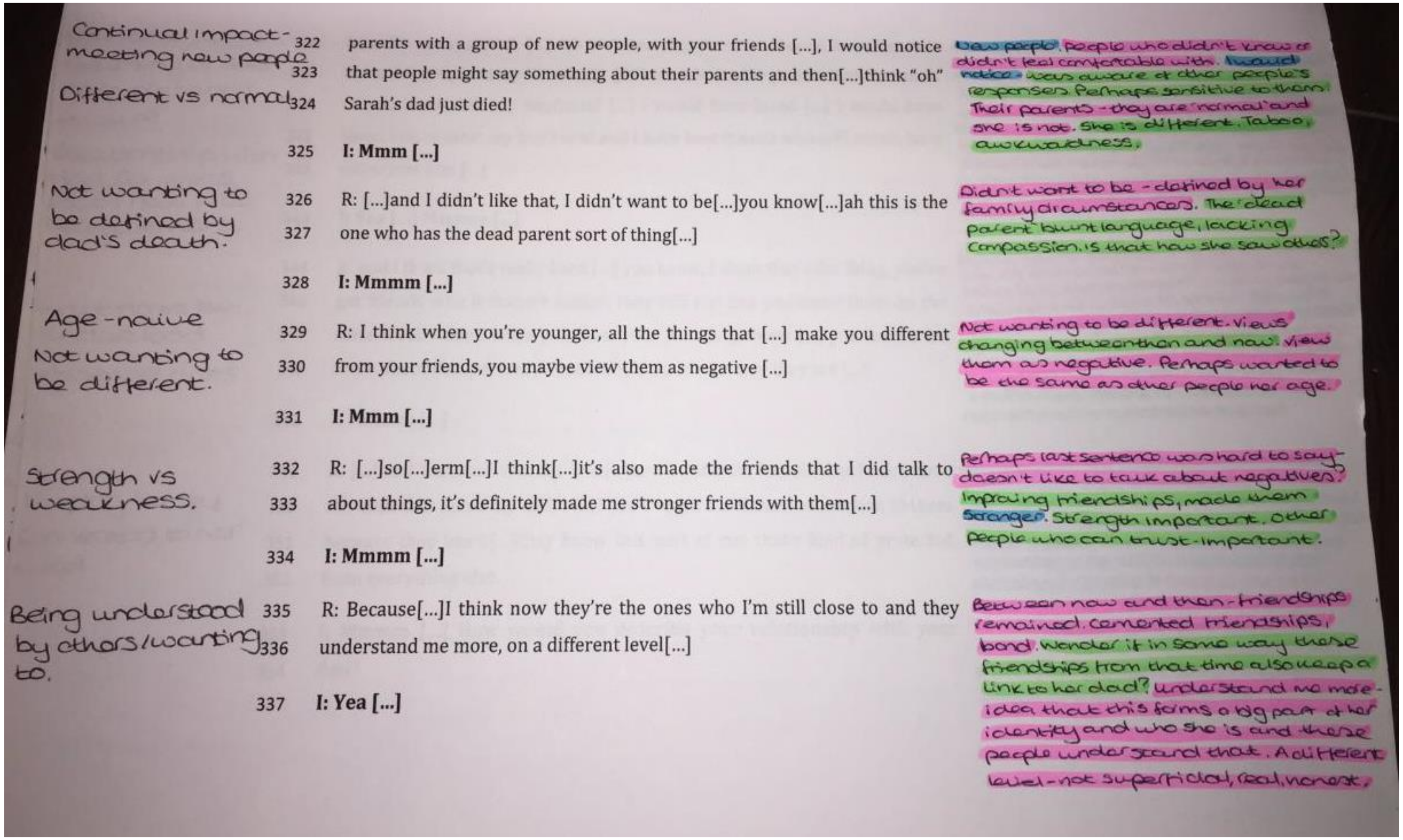
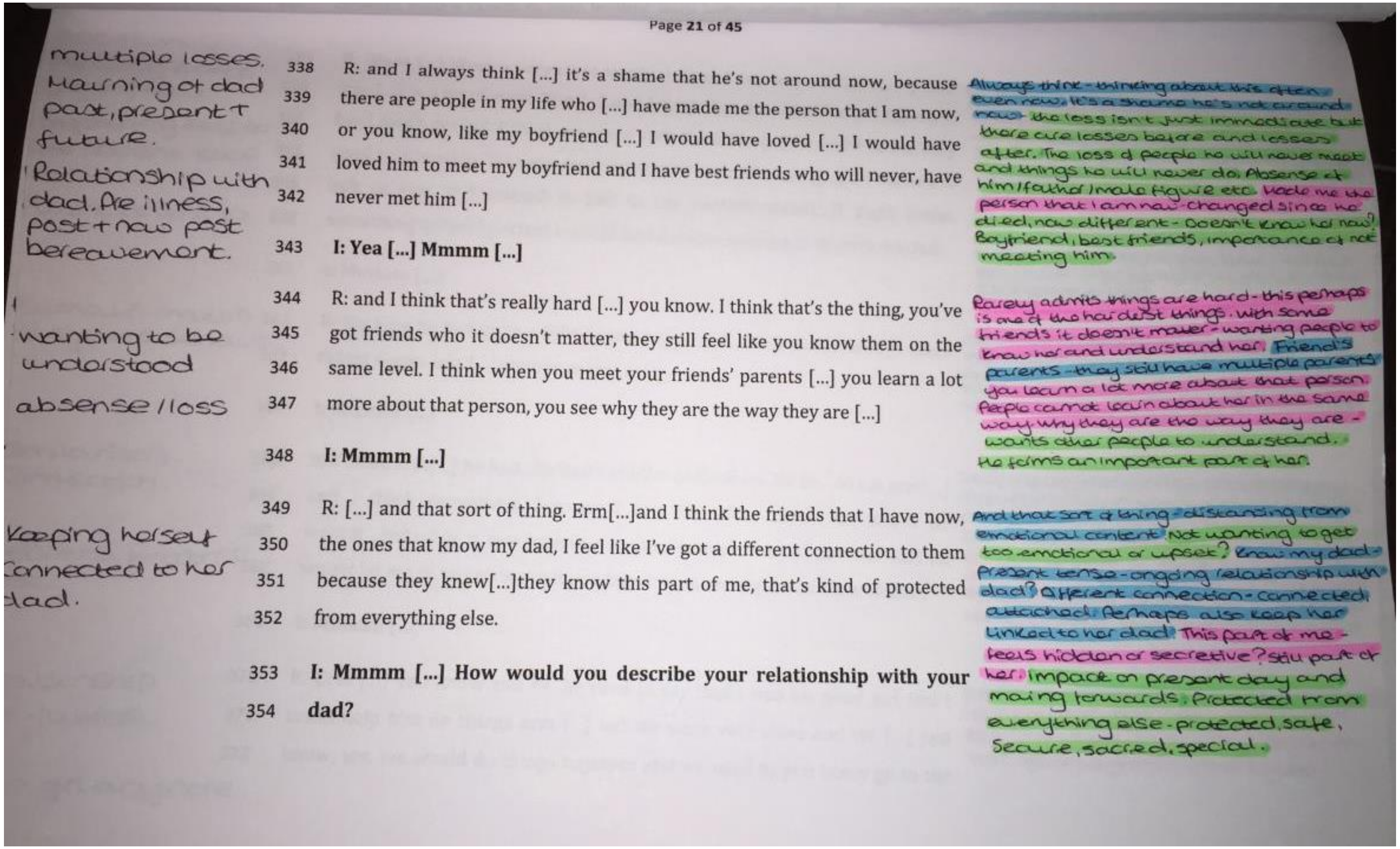
Treated differently to others the same age. Bereavement as an excuse.	lenient with me and I think, I didn't really take advantage of that, I wasn't really that kind of person who would like oh yea, I'll just pretend that I'm upset[...]er[...]	lenient with me - treated differently to other people the same age. Didn't really-want take advantage - there was an opportunity to not push yourself - there was almost an 'excuse'? Not that kind of person - mentioned again. what kind of people are there. Pretend - not truthful - the truth is important. Tone of voice again - mocking?
	I: Yea [...]	
Changing priorities Being treated differently by others.	R: [...] erm and I don't have to go to my classes. It certainly wasn't that kind of thing, but I think. It definitely, you know I definitely felt like oh well[...]if I miss this class it's not the end of the world because[...]my teachers don't mind or whatever[...]so[...]erm[...]I think it definitely meant that studying wasn't on the top of my list[...]	Don't have to go - there was a choice. Perhaps trying to defend her actions - feels they need to be defended/justified? It certainly wasn't - very definite. Doesn't want anyone to think she may have used it as an excuse. Definitely repetition. If I miss this class it's not the end of the world. Extreme language. Perhaps felt like at home world was ending. Teachers don't mind - permission granted. I think versus definitely meant. Studying wasn't on the top of my list. Studying was demoted.
	I: Yea [...]	
maintaining a sense of normality	R: I think that was [...] for me [...] you know, having some normality [...]	However school/college/university provided some 'normality'. This seems very important. Normality sought but not achieved? Perhaps craving to go back to how things used to be.
	I: Mmmm [...]	
	R: So [...] yea [...]	
(Divisive-dividing people Real friends vs. not real friends.	**I: and what about your relationships in terms of your friends and your peers at school at that time? Did you feel that that was impacted at all?**	
	R: Yea, definitely. I think it became very divisive amongst myself and my friends[...]I felt that there were[...]my real friends and then my friends	Divisive. Lots of dividers. Parents and children. Truth and lies. Honesty and deception. Real friends versus other people/friends. Real - concrete, tangible, dependable. Perhaps with deception hard to know what's real. Needed friends could trust as trust is perhaps hard at home?



Others reactions - hard to comprehend Similarities to mum + sister experiences Age gap chosing who to 'let in'	who[...] couldn't quite get their head around what had happened or[...]couldn't face talking about it. I think my mum definitely, had the same experience with her friends and I think my sister probably did as well. There were people who I didn't want to open up to, more to share anything with them because I thought [...] that they weren't people who [...] you know I wanted to let them in to that side of things [...]	Very diplomatically put. Hard to comprehend for others and self. Couldn't face talking about it. Potentially rejecting/hurtful. Mum also shared this experience and probably sister. Age gap brings her away from sister + closer to mother/parent level. Common experience. Easier if it is shared - not just me. Chosing who to open up to + <u>share</u> joint process. They weren't people who - stops self. Wanted to let them 'in'. Others on the outside not understanding. chosing who to 'let in'
	I: Mmmm [...]	
making sense of others reactions. normal vs unusual?	R: and I think some people, you know, can't handle that kind of things, and there were kids who would make nasty comments or whatever because it was an unusual situation [...]	Some people can't handle - tough for others very understanding and rational. Wonder if this would have felt different at the time. Making sense of other people's reactions. Nasty comments or whatever - dismissive - brushing over painful material. unusual situation - not normal. Justifying their reactions and responses.
Different vs normal	**I: Right [...]**	
Sympathy with bereavement	R: [...] which not many people erm... [...] deal with, and I think erm, when he died it was different. I think you get sympathy [...]	Not many people deal with - different - feeling different - not in a good way. When he died it was all different. I think you get sympathy. Bereavement is more relatable for other people, easier to emphathise. Where were you before? Sympathy - disingenuous?
	I: Mmm [...]	
Trying to understand the sympathy, is it genuine? unwanted ^attention	R: [...]you get that side and people, people are very sympathetic because, you know, oh, this girl has lost her father, erm[...] and I think[...] that was different because then, you know [sigh] [...]it [sigh] [...]it made me almost[...]sometimes you didn't want that attention if you talked about your	Reason for sympathy - perhaps it is not heartfelt but motivation behind it very sympathetic - from not understanding to <u>very</u> sympathetic. A big change in others. This girl has lost her father - putting herself into others shoes - trying to understand them. Removing herself from the situation. Sighs and pauses - really trying to understand. It made me almost - stops self - potentially angry/frustrated? Didn't want the attention - perhaps again not wanting to be different.



Continual impact - meeting new people Different vs normal	parents with a group of new people, with your friends [...], I would notice that people might say something about their parents and then[...]think "oh" Sarah's dad just died!	New people. People who didn't know or didn't feel comfortable with. I would notice - was aware of other people's responses. Perhaps sensitive to them. Their parents - they are 'normal' and she is not. She is different. Taboo, awkwardness.
	I: Mmm [...]	
Not wanting to be defined by dad's death.	R: [...]and I didn't like that, I didn't want to be[...]you know[...]ah this is the one who has the dead parent sort of thing[...]	Didn't want to be - defined by her family circumstances. The 'dead parent' blunt language, lacking compassion. Is that how she saw others?
	I: Mmmm [...]	
Age - naive Not wanting to be different.	R: I think when you're younger, all the things that [...] make you different from your friends, you maybe view them as negative [...]	Not wanting to be different. Views changing between then and now. View them as negative. Perhaps wanted to be the same as other people her age.
	I: Mmm [...]	
Strength vs weakness.	R: [...]so[...]erm[...]I think[...]it's also made the friends that I did talk to about things, it's definitely made me stronger friends with them[...]	Perhaps last sentence was hard to say - doesn't like to talk about negatives? Improving friendships, made them stronger. Strength important. Other people who can trust - important.
	I: Mmmm [...]	
Being understood by others/wanting to.	R: Because[...]I think now they're the ones who I'm still close to and they understand me more, on a different level[...]	Between now and then - friendships remained. Cemented friendships, bond. Wonder if in some way these friendships from that time also keep a link to her dad? Understand me more - idea that this forms a big part of her identity and who she is and these people understand that. A different level - not superficial, real, honest.
	I: Yea [...]	



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multiple losses.
Mourning of dad
past, present +
future.

Relationship with
dad. Pre illness,
post + now post
bereavement.

wanting to be
understood

absense / loss

Keeping herself
connected to her
dad.

R: and I always think [...] it's a shame that he's not around now, because there are people in my life who [...] have made me the person that I am now, or you know, like my boyfriend [...] I would have loved [...] I would have loved him to meet my boyfriend and I have best friends who will never, have never met him [...]

I: Yea [...] Mmmm [...]

R: and I think that's really hard [...] you know. I think that's the thing, you've got friends who it doesn't matter, they still feel like you know them on the same level. I think when you meet your friends' parents [...] you learn a lot more about that person, you see why they are the way they are [...]

I: Mmmm [...]

R: [...] and that sort of thing. Erm[...]and I think the friends that I have now, the ones that know my dad, I feel like I've got a different connection to them because they knew[...]they know this part of me, that's kind of protected from everything else.

I: Mmmm [...] How would you describe your relationship with your dad?

Always think - thinking about this often even now. It's a shame he's not around now - the loss isn't just immediate but there are losses before and losses after. The loss of people he will never meet and things he will never do. Absense of him/father/male figure etc. Made me the person that I am now - changed since he died, now different - Doesn't know her now? Boyfriend, best friends, importance of not meeting him.

Rarely admits things are hard - this perhaps is one of the hardest things. With some friends it doesn't matter - wanting people to know her and understand her. Friend's parents - they still have multiple parents. You learn a lot more about that person. People cannot learn about her in the same way. Why they are the way they are - wants other people to understand. He forms an important part of her.

And that sort of thing - distancing from emotional content. Not wanting to get too emotional or upset? Know my dad - present tense - ongoing relationship with dad? Different connection - connected, attached. Perhaps also keep her linked to her dad. This part of me - feels hidden or secretive? Still part of her. Impact on present day and moving forwards. Protected from everything else - protected, safe, secure, sacred, special.

Appendix N

Emergent themes for participant 1

Table 4.0 Emergent Themes - Transcript 1[2]

Line Number	Emergent theme
20	Hard to articulate feelings
21	Trying to make sense of experiences
21	Confusion
22	Ongoing process of illness
23	Trying to remember
23	Uncertainty
32	The use of Humour
32	Hesitation
32-38	The Story
35	Significance of Age
34	Sibling relationship (together, apart, together)
33	Pre-Revelation
32-38	Turning Point - The Talk
38	Shock/Unexpected
38	Leaving/being left
40	Sibling Relationship (we)
40	Acceptance/Lack of
40	Humour
41	Immediate Change
45	Turning Point
45	Sibling Relationship (we)
42	Deception - Information Kept Secret
46	Parent as protector
46	Humour
51	Diagnosis
49	Time Frame
50	Terminal - Finality
50	Broken
53	Post-Revelation
56	Hesitation
57	Brushing Over
58	Ongoing process of illness
60	Sibling Relationship (together)
61	Not Knowing what to do
63	Trying to understand
64	Comparing self to parents - what would I have done?
64	Hard to criticise parents

65	Age – Teenage
67	Sudden/shock
68	Acceptance - coming to terms
70	Age - School/college
72	Usual versus Unusual
72	Broken
72	Sibling relationship (not sure)
73	Unique experience - others don't understand
73	Uncertainty
76	People Involved (school/college)
78	Counselling - encouraged by school
80	Setting the scene - wanting to be understood
82	Help (being there versus not being there)
84	Age - That Age
85	Counselling - Stigma
86	Common versus uncommon
87	Weakness versus Strength
89	Counselling - Others perceptions
90	Other People - Everybody knew
92	Perceived versus real
94	Trying to make sense of experiences
95	Usual versus Unusual
97	Feeling Alone
98	Wanting to talk/share
98	Counselling - Expectations
98	The counsellor
99	Counselling - encouraged by mum
101	Counselling - removed from situation
103	Counselling - encouraged by mum
105	Parental influence versus teenage autonomy
108	Trying to make sense of experiences
109	Memory (adult versus adolescent)
110	Setting the scene - wanting to be understood
109	Overwhelming - little room
112	The counsellor
113	Counselling - Significance of time
114	Too soon for help
115	Coping (right way versus wrong way)
117	Age - context of others the same age
117	Overwhelming
120	Open up versus keep to self
121	The story
122	Counselling - Expectations
125	Difficulty Understanding
126	Counselling - Expectations

125	Trying to make sense of experiences
126	Counselling - Expectations
128	Counselling - Is this it
130	Counselling - wanting something
136	The Counsellor - she doesn't understand
136	Counselling - why am I here
137	Other people don't understand
139	Other people don't understand
139	Assumptions about others
141	Not knowing how feeling
143	Counselling - not going back
144	Time Period
146	Memory - frustration of trying to remember
146	Significance of Age
147	Age - context of others the same age
148	The phone call
149	Certainty versus uncertainty - terminal versus hope
152	sudden/shock of death
152	Being with him when he died
153	The terminally ill parent had changed - physical changes
157	The situation - the trauma
159	Strength versus weakness
160	Normality
162	Grief - denial/avoidance
162	Sudden attempt to return to normality
164	Trying to cope
167	Counselling - Stigma
167	Bereavement more acceptable
168	How others might perceive it
169	Just get on with it
170	Help not being helpful
175	Counselling - Uncaring/Rejecting
178	Telling the story
180	Emotional Strength
181	Avoidance/denial
182	Draining/Exhausting
183	Pre-Revelation versus Post
186	Deception - Information Kept Secret
188	Age – Young
190	Parent as protector
190	The truth
192	Impact on life since - career
192	Humour

194	The truth - finding more out as get older
199	Hindsight - learning with age
202	Not being told everything
206	Trying to understand
213	Nothing they can do - helpless
213	Different forms of loss
215	Parent as protector
215	Trying to make sense of experiences
216	Normal versus not normal
217	Unsuspecting - frustration at younger self
219	Respect for parents
222	Sibling relationship - separation from sister
229	Unspoken rules
230	Protecting each other
231	Confusion - not knowing how to feel
233	Protecting sister
239	Hindsight - learning with age
244	Physical and psychological aspects of illness
248	Sympathy
250	Anger
253	Trying to make sense of experiences
254	The terminally ill parent had changed - personality changes
260	Protecting each other
263	Physical and psychological aspects of illness
274	Changing Priorities
274	Outlook on life changed
274	Different to others the same age
276	Overwhelmed
276	Changing Priorities
280	Regret
282	Being treated differently by others - sympathy
286	Genuine - the importance of self and others being genuine
287	Being treated differently by others - sympathy
288	Bereavement as an excuse
293	Changing Priorities
294	Being treated differently by others - sympathy
297	Maintaining a sense of normality
302	Divisive - family and friends
303	Real friends versus not real friends
304	Others reactions - hard to understand
305	Coping - similarities and differences
306	Sibling relationship - the age gap
309	Choosing who to let in

311	Making sense of others reactions
313	Usual versus Unusual
315	Other people don't understand
316	Sympathy - when he died it was different
318	Sympathy - is it genuine
321	Unwanted attention - being different
322	Continuing impact - meeting new people
323	Different versus normal
326	Not wanting to be defined by experiences
329	Age – naïve
330	Not wanting to be different
333	Strength versus weakness
336	Being understood by others - wanting to be understood
338	Different forms of loss
338	Past present and future losses
341	Relationship with dad - pre and post illness
347	Wanting to be understood
347	Absence
350	Keeping connected to lost parent
355	Changing family dynamics
355	The way things were - ideal
355	Comparing self to lost parent - keeping the link
360	Parent closest to
363	Humour - makes things less serious/scary
365	Similarities to parent - keeping the connection
368	Secrets - innocence lost
370	Relationship with dad - pre and post illness
373	Together versus apart
374	Mourning - losses past, present and future
375	Humour
379	Similarities to parent - keeping the connection
380	Humour
383	Relationship with dad - pre and post illness
383	Age - not a little girl anymore
388	Sibling relationship - age differences
390	Protecting each other
389	Different levels of understanding within the family
391	Family roles and dynamics
392	Anger
394	Being in the middle - age and position within family
396	Family roles and dynamics
399	Changing views and perspectives
402	Strength versus weakness

403	Anger
403	Couldn’t stop - helpless
405	Not being chosen
407	Persuading dad - role reversal
411	Seeing parent differently
413	Doesn't want help - helpless
415	Understanding more with age
418	Illness - more understandable
421	Anger
424	Anger
427	Age – Teenage
428	Being in the middle - childhood and adulthood
429	Age - if it happened now
430	The truth - openness
432	Limitations of younger self looking back
434	Memories - good memories first
436	Memories - trying not to remember
440	Acceptance
441	The frame - time since happened
442	Regrets
447	Expected versus not expected
451	Developmental factors - growing up
452	Normality
453	Sudden versus Expected (it can be both)
457	Different to others the same age
461	Health care professionals - help
463	Misled - frustration - regret
467	Sudden death
471	End coming quickly
471	Help - nothing more they can do
474	Expected versus Sudden
481	Age - end of childhood
482	Age - being a grown up
484	Coping - feeling angry and upset
486	Nothing to compare it to
489	Brought them closer together
490	Coping - different ways
494	Coping - similarities and differences
496	Coping - similarities and differences
506	Help - best friend the biggest help
511	Being there - physically and emotionally
511	First person I called
518	Friend above all others
521	Help
522	Strength versus weakness

524	Being there - needing others
530	Coping - seeking someone who will understand
533	Help - most helpful
533	Real friends versus not real friends
537	Genuine - the importance of self and others being genuine
545	Age - between being a child and an adult
546	Being patronised - feeling patronised
549	Spoken to as a child
552	Want to be treated like an adult but understood as a child
554	Age - difficulties understanding
557	Cannot communicate inner world
559	Needing help
561	Needing help to understand and be understood
564	Anger
562	Admitting how you feel - guilt
569	Counselling - more interactive
572	Help - not adequate
573	Counselling - not age appropriate
573	Counselling - benefit not felt
575	Counselling - how perceived when young
575	Age - limitations of understanding
579	Despondent if don't feel useful
581	Understanding - adult versus adolescent
585	Adults and children are provided for - being overlooked
591	Memory boxes - tailored for children
595	Age - little children/young children
597	Age appropriate help
604	Patronised - age appropriate
607	Age - not a child
610	Uncertainty
611	More interactive
612	Patronised - age appropriate
614	In-between childhood and adulthood
619	Impact - more emotional person
621	Impact - changing perspectives
628	Impact - damaged trust - people may leave
630	Impact - relationships friendships
633	Impact - priorities
635	Impact - worrisome adult
638	Impact - loss of innocence
639	Worry
642	Fear of being helpless - having no control
644	Worry

645	Trying not to think about it
647	What if it happens to me
652	Mortality
654	Uncontrollable
658	Pre-illness (ideal)
658	Safety lost
661	Suddenness
662	Help-dad not there to help
669	Humour
699	Wanting to be understood
716	Age - difficult age
719	Age - easier when younger or older
725	Being left out - help
726	Overwhelming
728	Feeling neglected - help
735	Age - Developmental stage
738	Time of change
738	Overwhelming
741	Hard to identify how feeling
743	Making sense of how feel
748	Uncertainty of feelings
751	Parents illness as an excuse
754	Bereavement - understandable
757	Other people understand death - universal understanding
760	Being left alone

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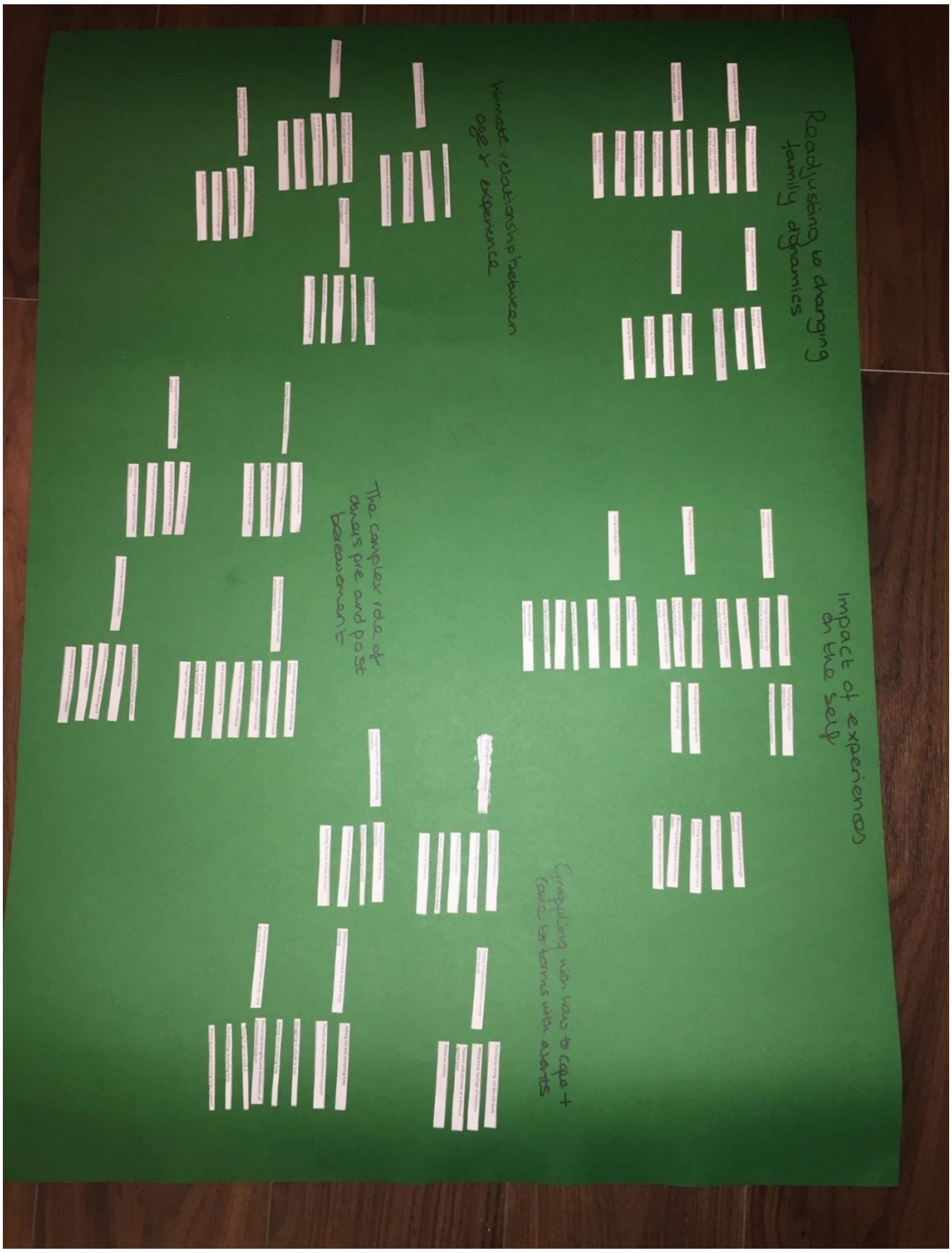
[2] A list of emergent themes was then drawn up for each of the six participants.

Appendix O

An example of the process of constructing a super-ordinate theme table for participant 1.

Figure 2. Photograph of theme table for participant 1[3]



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[3] The list of emergent themes were cut out so that they were on individual pieces of paper. These were then laid out onto a board and the clustering process (as described in the methodology) was carried out. From this, theme tables were created for each participant on separate boards. This was helpful in allowing a full view of all participant themes, so that clustering may occur. This allowed for flexibility, as theme clusters could be altered easily: individual theme labels were shuffled around the boards enabling easy rearrangement.

Figure 3. Closer photograph of a super-ordinate theme and subordinate-themes participant 1.

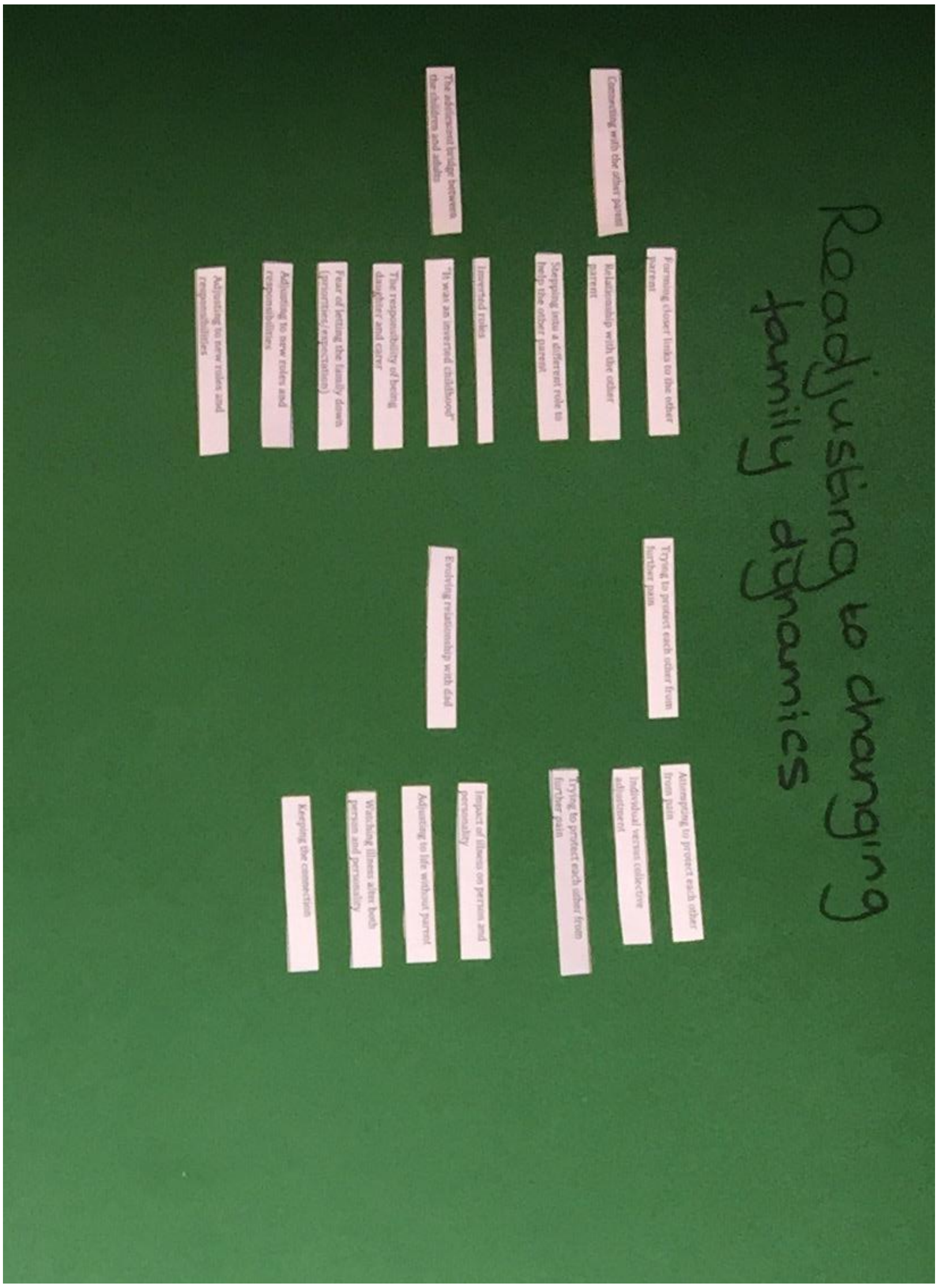

Table 5.0 Table displaying super-ordinate and subordinate-themes for participant 1[4]

Themes	Sub-Themes	Line	Keyword/Quote
Impact of experiences on the self	New sense of mortality	647.	I always worry the same thing will happen to me when I’m older.
		635.	It’s made me into a very worrisome adult.
		652.	I do worry about people getting sick, and people dying.
	Changing values and priorities	630-633.	They’re the things that are most important to me.
		622.	I try and worry less about things that don’t… seem so dire in comparison
		293.	If I miss this class it’s not the end of the world.
	Living with anger and regret	423-425	I do have anger towards him still.
		383	I stopped being his little girl.
		442	There was a lot of things that weren’t said
	Personal sentimentality following loss	338.	I would have loved him to meet my boyfriend.
		661.	He would have helped me with, I now have to fix it for myself.
		658.	Everything would always be ok as long as my dad was around.
		376.	We had a really fun relationship. He was a very fun person…
Grappling with how to cope and come to terms with events	Search for understanding and acceptance	440.	I don’t think I’ve fully accepted a lot of it yet.
		40.	We were like “no” that’s silly, don’t be silly.
		485.	We’d never had anything like that happen as a family.
		198.	There’s a lot of things I’ve learnt about my father and my family as I’ve got older that you see in hindsight.
	Trying to understand and convey inner world	742.	Am I feeling like this because of dad or … about exams?
		748.	Sometimes you’re not sure why you’re feeling that way.
		555.	You want to say something you don’t know how to articulate properly.
	Obstacles to seeking help	84.	Counselling is a funny word. There’s a lot of stigma attached.
		573.	At that age you want to get something out of it.
		723.	They think of smaller children rather than …older adolescents.
	Tring to “get on with it”	87.	It’s almost like a sign of … weakness.
		159.	Be strong and try to carry on as normal.
		180.	I didn’t have the emotional strength.
	The activist: healing through helping	192	I actually worked as a mental health nurse
		193-194	My first shift was in the ward where my dad had been
The relationship between age and experience	Developing a sense of awareness	717-722.	When you’re an adult you understand things a bit more.
		544.	You’re not a child and you’re not an adult.
		481.	That time definitely signalled the end of our childhood.
		427-428.	I was very much trapped between being an adult in a situation and being a child.
	Older adolescence: Life stage factors	329.	The things that make you different from your friends viewed as negative
		450.	You have your own relationships and things to deal with.
		735.	It’s that time you start going to clubs, and getting drunk with friends.
		115.	I was learning to drive…I was doing my A Levels…
	Impact of experiences on education and life direction	274.	It made me think studying is not really that important
		279-280.	It definitely meant I didn’t pay as much attention
		282.	My teacher became quiet accepting

		284. 286-287. 294-295.	I just found it hard to sit down and be in a classroom They were quiet lenient with me Studying wasn’t on the top of my list
	Wanting non-patronising help/support	606. 550. 559.	You’re too old for that kind of thing. You want someone to talk to you like a grown up. You need somebody to help you…
Adjusting to changing family dynamics	Connecting to the “other” parent	493. 63. 63.	My mum and I got a lot closer definitely I think my mum was very good She held it together really well
	The adolescent bridge between the children and the adults	34. 60-61. 222. 230. 234.	My sister was two years younger than me My sister and I didn’t really know what to do Tell me things rather than my sister We wanted her to know as little as possible She shouldn’t have to feel that way
	Protecting each other from further pain	215. 228. 190.	I think that was a way of protecting us That was an unspoken rule between my mum and myself They don’t always tell you the full truth because they’re trying to protect you
	Evolving Relationship with dad	436-438. 433-434. 423-425. 378-379. 383.	I try not to remember him during those years. You first and foremost remember the good things. I do have anger towards him still. Now I realise that I am actually very similar. I stopped being his little girl.
The complex role of others from diagnosis to post bereavement	Feeling different from others	326-327 329-330	This is the one with the dead parent All the things that make you different from your friends you maybe view them as negative
	The necessity of genuine support	302-303 303-304 311 333 335-336 505-506 513-514 533	It became very divisive amongst myself and my friends My real friends and then my friends who couldn’t… Some people, you know, can’t handle that kind of thing They understand me more on a different level It’s definitely made me stronger friends with them My best friend, she was brilliant She was the first person I called That’s what I found most helpful
	Not feeling understood by others	168. 169. 135-136. 139.	Oh everyone loses someone We don’t need to go and talk to anyone about it Why was I talking to someone who had no idea? You don’t understand anything
	The difference in responses post bereavement from pre bereavement	315-316 318 321	When he died it was different. I think you get sympathy People are very sympathetic Sometimes you didn’t want that attention.

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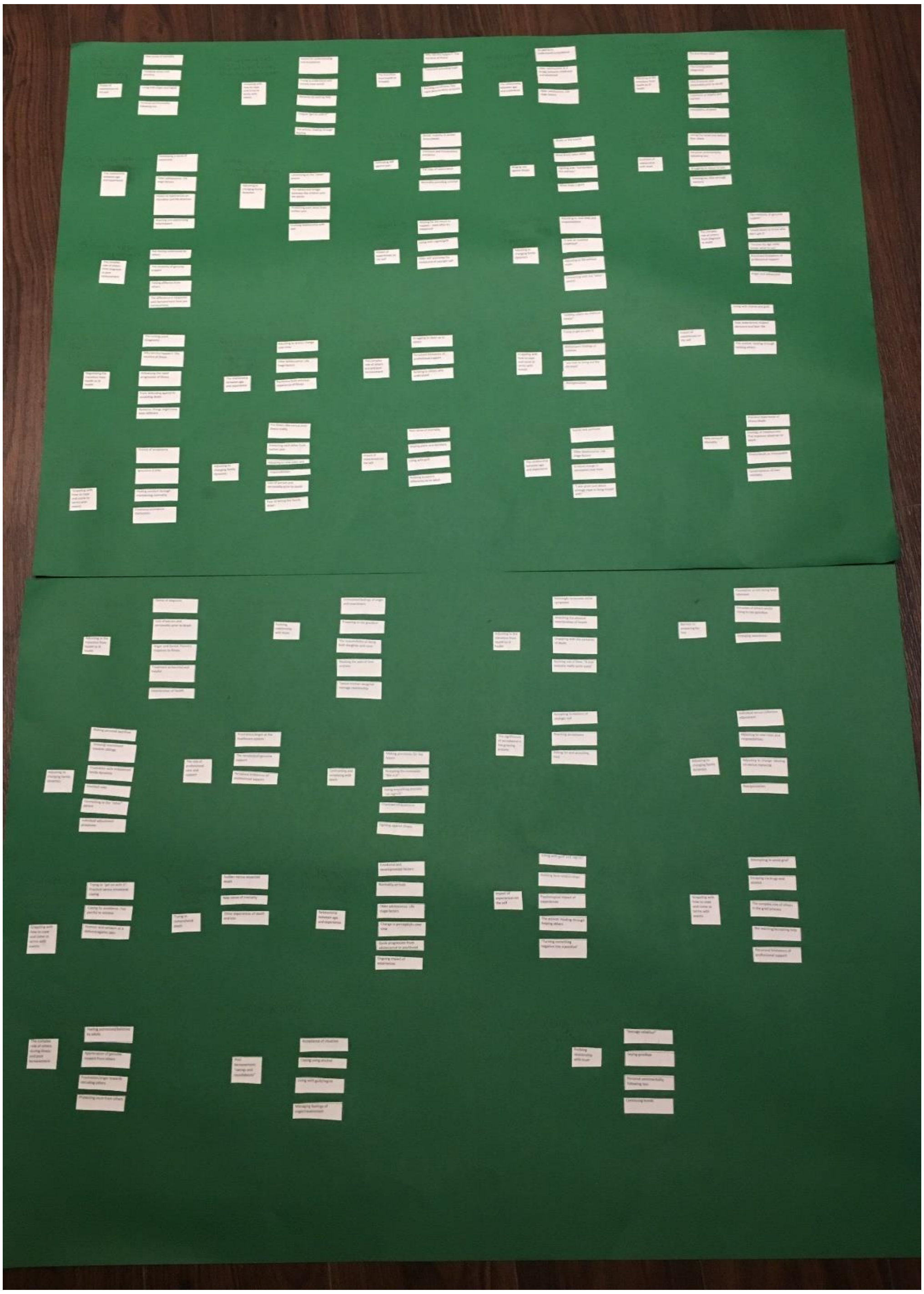
[4] Table demonstrating with greater clarity the themes constructed on the board (see Figure 2.).

Appendix P

Hand-constructed participant tables.

Figure 4. Photograph showing each of theme tables for all six participants[5]



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[5] The master theme table was created by viewing all participant boards simultaneously. The process outlined in the methodology was adhered to in order to create the master table, as demonstrated in table 2.0.