



Articles

Reflecting on Parental Terminal Illness and Death During Adolescence: An Interpretative Phenomenological Analysis

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Abstract

There has been little consideration of how adolescents experience parental terminal illness (PTI) and death and any continuing impact it may have on their lives. In particular, limited attention has been given to this group's perceptions and experiences of support during this period. This study explores the retrospective experiences of six individuals who had a parent diagnosed with a terminal illness (TI) during late adolescence. Their experiences are qualitatively explored in terms of their understanding, processing and adjustment to their parent's TI and death; both as an individual, and in the context of their wider family and social setting. 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. These were: changing family dynamics, grappling with adolescence and adjustment to loss, barriers to feeling/being supported and living with the consequences. Participants relate the profound impact that PTI during adolescence has had and continues to have on their lives. Study findings provide clinically useful information for healthcare professionals working with bereaved young people and those presently experiencing PTI. Implications are discussed in terms of service provision and design, including therapeutic recommendations for counselling psychologists and other professionals working with this group.

Keywords: parental terminal illness, bereavement, adolescence, counselling psychology, interpretative phenomenological analysis

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Approximately 41,000 young people, under the age of 18, are bereaved of a parent each year within the U.K. (Childhood 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; Phillips, 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 may be 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 et al., 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).

Developmentally, adolescence is a time of significant personal and social transitions and when a parent becomes unwell, these processes of change and growth may be side-lined; posing a threat to normal development (Ohannessian, 2007). In addition, adolescents may have more advanced cognitive and empathetic capacities than younger children; making them more aware of present and future losses as well as being more attuned to their loved one's physical and emotional pain (Kristjanson, Chalmers, & Woodgate, 2004).

It has also been frequently reported that adolescents may assume additional responsibilities within their family following a parent's terminal diagnosis (e.g. Christ, Siegel, & Sperber, 1994; Jantzer et al., 2013) and in Melcher, Sandell, and Henriksson's (2015) qualitative study, adolescents were depicted as being a "primary resource" for parents during this period (Melcher et al., 2015, p. 4). Ten teenagers (aged 14 to 19) were interviewed as part of the study, exploring how teenagers adapt to responsibility when a parent is dying, and participants described feeling responsible for their parents, siblings and everyday family life (Melcher et al., 2015).

Whilst the participants in Melcher et al.'s (2015) study spoke about their role in providing support, they also expressed a need for it, and parents were identified as a primary source of such support. However, friends, peers, teachers and professionals may also offer support for adolescents during this period, and seeking support has been associated with higher self-esteem, less behavioural problems and fewer symptoms associated with depression (Lawrence, 1996). 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) similarly 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).

Despite such findings, there appears to be a dearth of research exploring how these young people perceive supportive services and how they may go about asking for and accessing additional support. Such research may hold significant value as Malone (2016) contends that adolescents may be a group particularly reluctant to ask for help. Moreover, Rolls and Payne (2007) assert that children and young people are not a homogenous group and thus understanding how they can be best supported through bereavement is a challenging undertaking. It is subsequently important that Psychologists and practitioners from health, education and social care, who have a significant role in providing support for young people and their families, seek to fully understand the complex and continuing challenges they may face as well as what types of support may be of benefit.

In light of the literature and research reviewed, this study aims to investigate how individuals, who experienced PTI and bereavement during adolescence reflect and make sense of their experiences; with additional consideration given to their perceptions and experiences of support during this period. As such, this retrospective study, aims to provide relevant information that may inform policy, service provision and clinical practice.

Method

Design

A qualitative approach was adopted, as it aligned with the aims and objectives of the study. 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; whereby a further understanding of what it may be like to live through PTI and bereavement during adolescence was sought.

The researcher specifically employed Interpretative Phenomenological Analysis (IPA) as outlined by Smith, Flowers, and Larkin (2009). IPA 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).

In line with the chosen approach, semi-structured interviews were conducted with six participants and interviews were audio-recorded, transcribed and subsequently analysed (Smith et al., 2009).

Participants

Participants were required to have had a parent who received a formal diagnosis of a TI whilst aged 16-18 years. Given the retrospective design and the reflective nature of the data sought, only adults (i.e. over 18 years of age) were included in the study. Participants were six individuals, five female and one male, all of whom were Caucasian British and spoke fluent English as their primary language (see Table 1).

Procedure

Ethics clearance was secured by a university's ethics review panel and The British Psychological Society's (2014) Code of Human Research Ethics was reviewed and considered during the design and execution of this study. Participants were recruited by posting a recruitment advertisement on internet groups and forums and social networking sites. Contact was made with potential participants via telephone and permission was subsequently granted to send the study information pack via post; which included a copy of the recruitment poster, a detailed information sheet, consent and de-brief forms and a stamped return envelope.

The semi-structured interviews were conducted via telephone over 40 to 60 minutes and the hand-held digital recording equipment was introduced to the participant before being switched on. Participants were reminded that they had the right to withdraw from the study at any time prior to or during the interview, without providing a reason, and at the end of the interview, participants were provided verbally with debriefing information.

Table 1

Demographic Information for the Six Participants

Characteristic	<i>N</i>
Nationality	
British	6
Gender	
Male	1
Female	5
Parent diagnosed	
Father	3
Mother	3
Current age	
24-25	3
26-27	1
28-29	2
Age at TD	
16	2
17	1
18	3
Geographical location	
North East	2
North West	3
South West	1

Note. Age at TD = Participant's age at the time of parent's Terminal Diagnosis; *N* = Number of participants.

Data Analysis

Initially the transcripts were read for meaning; which 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 (Smith & Eatough, 2006). Initial noting encompassed outlining preliminary ideas, thoughts, and anything that appeared interesting or significant (Smith et al., 2009). These 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 (Smith & Eatough, 2006). These interpretative categories were then transformed into “emergent themes”, which served to draw out patterns of meaning from the transcript; with a focus on what was felt about what the participant was saying. As IPA is acutely “idiographic” each transcript was examined independently, allowing each case to be analysed in its own terms (Smith et al., 2009). The final stage of analysis involved the comparison and integration of themes for all participants. The 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.

Supervision and peer review were used to promote the credibility of the research (Smith & Osborn, 2008) and lent to further developing and substantiating ideas and themes. Additionally, 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 et al., 2009).

Results

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 and a renegotiation of roles and responsibilities was also presented. A change in family communication patterns was also outlined; 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 and 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.

Changed Beyond Recognition

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 expressed the emotional and psychological impact of these changes.

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)

The participant's statement that "he wasn't really himself" reflects a sense of her father being lost. The description of his condition demonstrates how distressing it was to witness, and it may be that presenting her father as not being "himself" helps her to cope.

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, participants appeared to attempt to separate their parent from their illness as a way of making sense of upsetting physical and dispositional changes. There is a sense of the parent being lost and grieved for prior to bereavement.

Strengthened Relationships With Surviving Parent

Most participants spoke about how their relationship evolved with their surviving parent; particularly over the months and years following bereavement. They referred to finding new ways of relating to each other and establishing a deeper connection. Participant 4 reflects on her relationship with her father.

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)

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.

New Roles and Responsibilities

Participants shared similar experiences of adopting new roles and responsibilities within their family following their parent's diagnosis.

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 and helping her parents to look after her younger siblings creates a levelling of roles.

Participant 1 reflects on the difficulty associated with taking on more responsibility.

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

She describes not just being in between childhood and adulthood but feeling "trapped"; which may also reflect the nature of the TI.

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.

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. 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 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 seemingly provides an additional layer of insight. The use of "full truth" alludes to an "incomplete truth" that she may have been told. Yet, she does not use language with negative connotations such as lie or conceal, and there is therefore a sense of understanding that her parents were trying to protect her.

Super-Ordinate Theme: Grappling With Adolescence and Adjustment to Loss

All participants spoke about the complexities associated with being an adolescent alongside being the child of a TI parent. It therefore appeared as though being an adolescent, impacted how they experienced PTI (e.g. understanding and coping), and PTI impacted how they experienced adolescence. Subsequently, there seemed to be a complex interplay between how they simultaneously negotiated these challenges.

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.

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)

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 an emphasis on not knowing and for the majority of participants, their age and lack of prior experience seemingly hindered a complete understanding PTI and its consequences. It was also apparent that information provided was sometimes inaccessible.

Finding a Means of Coping

Participants spoke about coping or trying to cope during their parent's TI. Most of the participants appeared to derive some comfort from the stability and familiarity of the everyday routine, as they attempted to "carry on". Yet, 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.

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)

Participant 6: *"In the [...] that moment then it was like well this is a necessity. It needs to be done. Just do it".*

Continuing life as normal may provide a degree of certainty and controllability which has been taken away by TI. However, there is also an association between strength and carrying on, and there may subsequently be a perception of difficulty and distress as denoting weakness.

Participant 4 offers a contrast.

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

The participants who turned towards drugs and alcohol, appeared to want to escape from their inescapable situation; turning away from normality and perhaps attempting to enter a different reality. These participants also reported distant or conflictual relationships with their surviving parent, and it may be that they felt a heightened or more overwhelming sense of loss in losing their primary caregiver.

"It Was Kind of an Awkward Difficult Phase"

Participants referenced challenges associated with adolescence during their interviews, presenting their age and experiences as being intrinsically entwined within this "awkward difficult phase".

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 those things that are going on when you're that age [...]"* (1.8.115-118)

Presenting some of the milestones of adolescence serves to highlight the complexity of this period and creates a sense of being overwhelmed. PTI is not presented as a separate challenge but rather being added to the perplexity of the adolescent experience. Participants also expressed finding it difficult to understand or articulate what or how they were feeling during this complicated period.

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. Particular barriers to feeling supported were presented, which included: Finding other adolescents who could understand and relate to their experiences, perceptions of social stereotypes and stigma and limitations of support services.

“No-One my Age Really Knows What to Do”

Participants reported that other adolescents struggled to understand and relate to their experiences, and subsequently to them.

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)

For participant 1, some friends were supportive, whilst others were not and there is a sense of others being insensitive or unknowing in how to approach the topic of her father's illness.

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.

Stereotypes and Stigma

Participants reflected on their perceptions of stereotypes and stigma associated with their parent's illness and death. 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: *“[...] I didn't want to be [...] you know [...] ah this is the one who has the dead parent sort of thing [...]”* (1.20.326-327)

Participant 1 expresses concern around how she felt that she might be being perceived by her peers. She further noted, how as an adolescent, you perhaps may not want to be seen as being different; and that points of difference are primarily viewed as negatives. Participant 1 also 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 subsequently depicted as almost something to be embarrassed by; a symbol of weakness. The emphasis on “that age” also alludes to the specific social context of adolescence, whereby certain things are acceptable or unacceptable.

Participant 5 similarly alludes to acceptability.

Participant 5: *“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)

Participant 5 references perceptions of social norms or constructs around gender, which may potentially have pathologised his emotional response to significant loss. Other participants similarly discussed potential barriers to support posed by their social and wider cultural environment.

[Counselling] “It’s a Good Concept”

Participants reported 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 [...]. But it was, it was really, really lengthy the time I had to wait”* (4.30.472-478)

Participant 5 describes 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 expression alludes to the fact that it did not seemingly matter what his difficulties were. The idea of six sessions is presented as constraining and perhaps he feels as though the magnitude of his experiences cannot be constrained in this way.

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 and support or information provided in or via school/college was not mentioned.

Super-Ordinate Theme: Living With the Consequences

All participants spoke about the impact that their experiences of PTI have had and continue to have on their lives and they described a variety of struggles or consequences of their experiences that they may not have had to contend with had their parent not become TI. This superordinate theme highlights these past, present and future struggles.

Guilt and Regret

Most participants spoke about how they looked back on their experiences with some sense of regret; expressing how they could have done something or responded to something differently.

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 appears almost to be reprimanding her younger self. She states that her guilt is the most difficult thing to deal with, and this appears similar for participant 5.

Participant 5: *“Incredibly shameful, embarrassing, guilty thing, [inhales] um, but you, how do you explain to your big sister and your loved ones who are around you, helping her survive and helping you to cope 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 doesn’t seek to understand or empathise with his younger self, and there is a sense that his thoughts are unjustifiable or unforgiveable. In describing others as “helping her survive”, they are presented as good and he as bad.

Feelings of guilt and regret appeared to be pervasive for the participants and they did not seem to attempt to make sense of their thoughts or actions as those of their younger adolescent selves. It may be that their inability to relinquish their guilt reflects an inability to forgive themselves.

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 2 describes ongoing concerns about people becoming ill or dying.

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 over-protective 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 and it appears that death has evolved from being perceived as an abstract concept to something that is not only possible but probable.

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 for them as adults; presenting loss and grief as processes beginning around the time of diagnosis and continuing into their present and future lives. Most participants spent some time during the interview reflecting on the absence of their parent in their lives.

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)

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, and her tenses fluctuate between past, present and future which seemingly reflects the trajectory of her grief.

Participant 4: *“later on, we, we started to get close again but obviously then she passed away, so [...]”*
(4.16.246-247)

For participant 4 there is a sense of what might have been and on what now will never be. It may be that the participants still struggle to accept the finality of their parent’s death.

Discussion

This study aimed to explore how individuals, who had a parent diagnosed with a TI during adolescence, reflected on and made sense of their experiences and the subsequent impacts on their lives; with consideration also given to their perceptions and experiences of support. Using an IPA approach, analysis yielded insights into these experiences from the perspective of six individuals.

Blank 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 these findings, 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.

Adolescents may struggle to understand aspects of PTI due to the language and terminology used. Graham & 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, & Fletcher, 2004); who have less prior knowledge and life experience. Participants in the current study described incidents of failing to comprehend medical terminology (e.g. Stage 4 Cancer) and contextual information (e.g. a parent moving from hospital to hospice care), and it appeared as though the information given was not always accessible or age-appropriate.

However, it may be difficult for parents to inform and communicate with their children about PTI, particularly in deciding which information to convey, when to present it and what language to use (Houldin & Lewis, 2006; Turner et al., 2007). Difficulties in communicating effectively with adolescent children may further be confounded by adolescents projecting an image of independence and understanding (Malone, 2016); which may lead to incorrect presumptions about adolescent understanding. Participants in the present study reported being sensitive to feeling patronised by adults and appeared unlikely to ask for clarification, even when needed.

Results from the present study also suggest that adolescents may attempt to cope with PTI in a variety of different ways, with some appearing to derive comfort from maintaining normality (e.g. focusing on daily life and routine). Helseth and Ulfsaet (2003) pose that engaging in activities reflective of life prior to diagnosis may provide a useful distraction for young people; preventing them dwelling on their parent’s illness and its implications. In this respect, maintaining normality may be viewed as a form of active (Herman-Stahl & Petersen, 1996). How-

ever, results from the present study suggest that maintaining normality may be demonstrative of active or avoidant coping, as there may be an element of reluctance to accept that normality has changed.

Adaptive coping styles such as active (e.g. Ebata & Moos, 1991) or support-seeking (Herman-Stahl & Petersen, 1996) have been linked to positive adjustment and a lesser likelihood of experiencing depressive symptoms (Lawrence, 1996). The opposite can be said for less adaptive coping styles, and within the current study two participants notably demonstrated more avoidant coping (Herman-Stahl & Petersen, 1996); through use of drugs and alcohol. These participants appeared to feel particularly overwhelmed, and it may be that this relates to losing their primary caregiver; as both participants depicted a distant or conflictual relationship with their surviving parent.

Melcher et al. (2015) depict adolescence as a stressful period where teenagers strive to create an identity independent of their families. They further suggest that a parent's diagnosis of a TI, potentially shifts the adolescent's focus back towards their family. Participants in the present study highlight how the complexity of adolescence was further compounded by their parent's terminal diagnosis; creating a struggle in balancing priorities and responsibilities. Participants subsequently described the various tasks and challenges associated with both adolescence and PTI, and the difficulties they experienced in terms of understanding, processing and articulating what and how they were feeling during this complex and challenging period.

The centrality of the family system is highlighted in much of the literature and research in this area. Indeed, Bugge et al. (2009) suggests that "*the anticipated death of a parent from a terminal illness is a family crisis from any perspective*" (p.3487). An area of significant change for the participants in this study, 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. The parent's worsening health necessitated the renegotiation of household roles and responsibilities, and the participants seemingly rose to meet their family's needs. However, whilst they demonstrated a strong sense of resilience in being able to adapt to their new position, as was also reported by Melcher et al. (2015), a sense of struggle in managing significant responsibility prematurely was also apparent.

Wong et al. (2010) contend that communication within families may be of increasing importance where a parent has been diagnosed with a serious illness and open communication within families regarding illness has been linked to children's resilience and overall sense of wellbeing (Thastum et al., 2008; Wong et al., 2010). Yet, participants in the current study suggest that following their parent's diagnosis, information-sharing and communication reduced as family members attempted to protect each-other from additional distress. However, findings from previous research intimates that reduced information-sharing and communication may be linked to decreased family cohesion; even when motivated by limiting distress (e.g. Tercyak, Streisand, Peshkin, & Lerman, 2000).

Adolescents may in general, have less experience of serious illness and death than adults, and may be less equipped to respond to those who have. In terms of social support, participants stressed how other adolescents struggled to respond helpfully to their circumstances, and there was a sense of being different and in some cases isolated. A further sense of stigma or stereotyping was discussed in relation to accessing supportive services; whereby seeking support appeared to be associated with weakness.

Moreover, whilst all participants expressed how the idea of seeing a counsellor or psychologist for therapy appealed to them, lengthy waiting times and limited session numbers were presented as considerable drawbacks. 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, 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.

Results from this study suggest that the impact and/or consequences of PTI and bereavement during adolescence may be long-standing and far-reaching. Stroebe et al. (2014) name guilt and regret as commonly cited reactions to the loss of a loved one. However, for the participants, it appears their feelings of guilt and regret have not abated over time. Rather, now as adults, they seemed to be more aware and critical of their younger selves and perceived failings. Results from this study also intimate how the participant's experiences led TI and bereavement to become more than abstract concepts but rather certain life occurrences, leading to greater fear or anxiety around personal health and the health of loved ones. Phillips and Lewis (2015) similarly reported how adolescents (aged 11-15) of advanced cancer patients expressed fears around being diagnosed with cancer themselves.

The present study has several limitations. As it only included 6 Caucasian British participants, it cannot be understood as representative of all individuals who had a parent diagnosed with a TI during adolescence and it should also be considered that the current study did not make distinctions between types of TI diagnosis. Also, no distinctions or differentiation has been made between pre/post bereavement experiences and as such, participant accounts reflect a broader exploration of experiences.

Moreover, significant consideration was not given to cultural or religious factors. Cultural and religious background of adolescents may be of significance when considering their response to PTI and death (Robin & Omar, 2014) and the characteristics of "normative" grieving responses may vary significantly according to cultural and religious background (Batten & Oltjenbruns, 1999).

Retrospective accounts were used in the present study and this has facilitated a reflective exploration of PTI and bereavement during adolescence, as well as the subsequent and ongoing impacts of experiences; from the perspective of individuals now in adulthood. As such, results may offer a different perspective to those of adolescents themselves, currently living through PTI and bereavement. Also, whilst retrospective accounts are frequently used in both qualitative and quantitative research, it has also been asserted that individual memories are altered and shaped by a variety of factors (Schuman, Rieger, & Gaidys, 1994); intimating that memories and perceptions may alter over time.

Finally, 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 (Opdenakker, 2006). Telephone interviews have been considered particularly useful where traumatic and sensitive topics are being discussed (Trier-Bieniek, 2012). However, several limitations of telephone interviews have been referenced, most particularly the absence of visual cues (Garbett & McCormack, 2001).

Conclusions and Future Directions

Results from this study suggest that adolescents may be susceptible to becoming inadequately informed about PTI, particularly in terms of being prepared for later stages of illness and bereavement itself. However, [Miller \(2008\)](#) suggests that the more information adolescents receive regarding their parent's illness, the fewer psychological symptoms they are likely to experience. Yet, it may be difficult to establish the level of an adolescent's understanding; given their outward demeanour and reluctance to seek clarification. It may therefore be important for parents and those working with this group to take time in providing adolescents with clear and age-appropriate information regarding PTI; particularly in terms of redefining medicalised terminology.

Practitioners may also benefit from assessing adolescent coping skills and mechanisms, as findings suggest that adaptive coping (e.g. active or help-seeking) may be protective for adolescents. Conversely feeling overwhelmed following a TI diagnosis or post-bereavement may be related to more escapist coping (e.g. the use of drugs and alcohol). The nature of parental relationships might also be usefully explored, as participants who described feeling overwhelmed and unable to cope depicted a distant or conflictual relationship with their surviving parent. Future research might further consider the relationship with the surviving parent as a potential risk/protective factor for adolescents.

U.K. bereavement services are diverse in terms of their location, service offerings, organization, waiting times, funding and the interventions offered ([Rolls & Payne, 2007](#)). 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 further consideration should be given to pre-bereavement care for adolescents.

[Rolls & Payne \(2007\)](#) stress the importance of the experiences of service users in understanding, improving and designing effective services and interventions for bereaved young people, 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.

Competing Interests

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Ethics Approval

In accordance to the BPS Human Research Ethics (BPS, 2010), all ethical guidelines, following university ethics clearance, were adhered to.

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