

SOCIOLOGY OF HEALTH & ILLNESS

Sociology of Health & Illness Vol. xx No. xx 2020 ISSN 0141-9889, pp. 1–13
doi: 10.1111/1467-9566.13086

‘My life’s properly beginning’: young people with a terminally ill parent talk about the future

Nicola Turner 

School of Health Sciences, University of Nottingham, Nottingham, UK

Abstract This paper explores how young people who are living with a parent who is dying talk about the future. Drawing on a qualitative, interview study, I argue that young people are able to move imaginatively beyond the death of a parent, and in doing so, to maintain a sense of biographical continuity. While thinking about the future, most were able to generate an alternative to the ‘harm story’ typically associated with parental loss. Furthermore, the facility to engage with parental absence in the present enabled young people to make sense of living with dying, and gave meaning to their imagined futures. These findings suggest that young people’s narratives of the future may act as a symbolic resource to draw on, albeit one requiring adequate material and social resources to construct. The paper extends the notion of continuing bonds derived from post-bereavement accounts to suggest that relational experiences of the dead begin prior to bereavement, and may facilitate everyday living in anticipation of significant loss. Enabling young people to imaginatively explore the future may support them in getting by when they are living in these difficult family circumstances.

Keywords: death and dying, biographical disruption, family care, young people, narrative method

Introduction

The death of a parent tends to be viewed as an extraordinary experience for young people in the UK, yet every year around 24,000 parents of young people aged under 18 die, with between 60 and 75 per cent of deaths being expected due to chronic and/or terminal illness (Penny 2018). In a survey of young people age 10–14, 43 per cent said someone close to them had died recently; for 4 per cent of young people, the death was of a parent (Jamieson and Highet 2013). Whilst parental death is not wholly exceptional in the lives of young people, little is known about how young people anticipate significant loss in and through their family lives, or the resources young people draw on to ameliorate the effects of living with a parent who is dying.

Based on an exploratory study of the family lives of 10 young people with a parent at the end of life, this paper explores how young people talk about the future when they are aware their parent’s prognosis is limited. I examine whether young people are able to articulate, and even look forward to, a future in which their parent is no longer living, and I consider how the absent parent features in young people’s accounts of the future. In doing so, I draw attention to the potential for young people’s future lives to assist them in ‘getting by’ (Backett-Milburn *et al.* 2008), and in making sense of difficult family circumstances in the present.

Previous research on young people's prospective experiences of living with a terminally ill parent has been limited, and has often adopted an approach based on psychometric testing to identify and measure harm at the individual level (Morris *et al.* 2018, Walczak *et al.* 2018). The focus has been on the damage inflicted on young people across a range of dimensions extending into adulthood (Lytje and Dyregrov 2019). Whilst the significant challenges associated with living with a parent who is dying should not be overlooked, the presumption of damage both in the present and in the future overlooks young people's agency in resisting harm and in deploying their resources to increase the potential for more positive outcomes. As Ribbens McCarthy *et al.* (2013: 11) point out, the application of a dominant 'harm story' to young people's encounters with loss obfuscates the diversity of young people's experiences, and offers little room to manoeuvre for young people who want to get on with their lives outside of a framework of on-going trouble.

The argument for applying an alternative lens to the study of young people's experiences of parental terminal illness is supported by researchers who comment on the paucity of a pathological model of maladjustment to describe how young people contain these experiences in their everyday lives (Phillips and Lewis 2015, Rainville *et al.* 2012). Research indicates that, far from being passive victims of their family circumstances, young people purposively engage with a number of strategies to negotiate everyday life with a parent who is dying; for example, seeking to maintain a sense of normality by adhering to usual routines, and keeping busy with activities outside the home (Hanna *et al.* 2019, Sheehan *et al.* 2016). Young people's access to formal services is often limited (Franklin *et al.* 2019), although some young people report that they prefer to draw on family and friends for emotional support (Ellis *et al.* 2016). Nevertheless, talking about a parent's illness and anticipated death can be difficult, and young people may sometimes avoid communication in order to minimise distress to themselves and others (Turner, 2018, Dalton *et al.* 2019). Sheehan and Draucker (2011) draw attention to the salience of time to young people's experiences of living with anticipated loss. Given the limited amount of time remaining to spend with their parent, time becomes a resource young people and family members use to help prepare for a parent's death.

The dimension of time, with its axes of change and continuity, underpins two conceptual models that have been applied to understanding how people make sense of personal and relational experiences of illness and loss. Bury's (1982) notion of biographical disruption describes how the onset of chronic, life-threatening or terminal illness challenges a person's sense of self, requiring the marshalling of resources to restore a coherent biographical narrative. The concept of continuing bonds (Klass *et al.* 1996) explains how on-going relationships with the deceased can be maintained; reinforcing relational identities and enabling adjustment to loss. These concepts shed light on how past, present and anticipated future selves can be co-constructive in responding to loss, and offer the potential for developing new perspectives on young people's experiences of living with a parent who is dying, beyond the dominant 'harm story'.

Biographical disruption

Bury's (1982) concept of biographical disruption describes how a diagnosis of chronic illness interrupts the individual's expectations and plans for the future. The experience of illness disrupts taken for granted assumptions and routine behaviours and threatens the individual's sense of self and their relationships to others. Bury (1991) pointed out that the level of personal, social and economic resources available to an individual influences their ability to reconstruct a coherent narrative that takes account of the vicissitudes of a chronic condition. Bury thus made an important contribution to understanding illness as not only a biomedical event, but also a biographical, relational and social phenomenon (Locock and Ziebland 2015).

The concept of biographical disruption has been extended to explore other health events and conditions, including life-limiting illness (Trusson *et al.* 2016, Wilson 2007). It has also been applied to family members of people with chronic or life-limiting illness; for example, Greenwood and Mackenzie (2010) found evidence of biographical disruption in family carers of stroke survivors.

Research suggests that living with a parent who is dying disrupts young people's taken for granted assumptions about family being present to provide care and support. (Turner and Almack 2019) found the absence of family members in these circumstances challenges the moral narrative of a functional family as one that puts the needs of children first. Instead, the everyday routines and practices of family life adapt to take into account the ill parent's growing need for care, with young people taking on more responsibilities for giving care (Thastum *et al.* 2008).

Pearce (2011) found that the timing of a parent's death influenced the extent to which parental loss was experienced as a biographical disruption in the retrospective accounts of young women. Those who were ready to leave home and pursue their own goals were less likely to regard future plans as having been derailed by their mother's death. Instead, assuming control of their biographical narrative was interpreted as a means of reasserting agency in circumstances that had been characterised by uncertainty and a loss of control.

Approaching the anticipated loss of a parent as a biographical disruption sheds light on how young people's experiences of change and continuity may be interwoven to restore a coherent self and make sense of troubling events in the present. For example, whilst young people's everyday family lives may be disrupted by parental terminal illness, the ability to maintain continuity of plans and aspirations appears to support young people in getting on with their lives, and merits further attention.

Continuing bonds

The notion that the deceased continue to occupy a presence in the everyday lives of the living has been widely accepted in many historical, geographical and social contexts, albeit the meaning and form of 'presence' vary within and across these dimensions (Klass 2015). Ribbens McCarthy and Prokhovnik (2014) suggest that, in an increasingly secular UK society, institutionalised models of grief in the late 20th Century tended to emphasise the importance of 'letting go' of the deceased in order to make a healthy adjustment to a future without them. In contrast, the iteration of continuing bonds put forward by Klass *et al.* (1996) re-focussed attention towards the embodied, physical and emotional practice of continuing to relate to, and care for, a person after their death.

Claburn *et al.* (2019) carried out a narrative review of how young people continue to maintain a relationship with a deceased family member. They identified three over-arching themes representing the different modalities and means by which young people 'do' continuing bonds: young people form purposeful, *intended* connections through the use of stimuli to trigger a cognitive or affective memory of the deceased person; they make *unintended* connections in the form of spontaneous, sensory experiences of the deceased person; and create *internalised* connections through adopting aspects of the deceased person's values or beliefs.

The process of continuing bonds with a parent after their death may be experienced by young people as positive, enabling them to create meaning from loss and accommodate changes in their family circumstances (Hansen *et al.* 2016). However, some young people report ambivalent or negative consequences of continuing bonds; Andriessen *et al.* (2018) identified a strong sense of anger or injustice associated with an on-going connection to a deceased parent, and the experience of unintended connections in the form of unexpected, visual or auditory 'hauntings' can be distressing (Tyson-Rawson 1996).

Maddrell (2013: 501) suggests that, through a dynamic process of continuing to re-negotiate relationships between the living and the dead, a tangible form of *absence-presence* of the deceased is constructed and maintained. In setting out to map the often intangible and shifting experience of loss and grief, Maddrell (2016: 184) seeks to offer a resource for those who are personally or professionally engaged with 'the lived sense-making and way-faring associated with bereavement, mourning and remembrance'.

One aspect that has potentially been under-investigated in applying the continuing bonds model has been the temporal dimension to loss, in that it is generally assumed relational experiences of the dead commence at the point of death. Yet many deaths are anticipated; for example, young people in the current study were aware their parent had a terminal illness and a limited prognosis. In 'way-faring bereavement', it may therefore be helpful to understand more about the direction of travel in relational identities prior to death, and the effects of anticipating a death on the experience of maintaining bonds with the deceased.

The current study seeks to extend conceptual models of biographical disruption and continuing bonds by exploring how change and continuity in family relationships and relational identities are reflected and understood in and through the biographical narratives of young people when a parent is dying. In these circumstances, thinking about the future obliges young people to reach beyond their parent's death to imagine a time when they will no longer be with them. How young people accommodate the absence-presence of the parent in making sense of their own lives is hitherto unexplored in young people's prospective accounts of living with anticipated loss. The following section introduces the prospective study of young people's experiences of parental terminal illness on which this paper is based.

Methods

The *Caring to the End* study set out to explore the family lives of young people when they are living with a parent who is at the end of life. The main aims were to investigate:

- 1 The meanings and everyday experiences of 'family' for young people when a parent is dying.
- 2 Young people's experiences of giving and receiving family care.
- 3 The resources young people draw on to help them get by in these challenging circumstances.

This paper reports on the study findings in relation to young people's use of resources; in particular, on how young people draw on their accounts of the future in making sense of living with a parent who is dying.

Since the study was concerned with exploring the meanings attributed to experiences and events, a qualitative, narrative approach was adopted based on in-depth, semi-structured interviews with young people who were living with a parent at the end of life. The study was granted ethical approval by the University's Research Ethics Committee, and the appropriate ethical and research governance approvals were obtained for each of the eight services who agreed to identify potential participants (three hospices, three young carers' projects and two palliative and end of life care services). Young people were eligible to take part if they were:

- 1 Aged between 13 and 21. During this period, young people in the UK are required to engage in a series of deliberations through the education system regarding their plans for the future, therefore is a significant time for exploring how parental terminal illness impacts on young people's sense of their own lives, both in the present and in the future.

- 2 Living with a parent who had been assessed by a medical practitioner as terminally ill, and as having less than a year to live.

The decision to approach young people via a service already known to them was taken in response to the sensitivity of the research topic, and was intended to ensure young people were introduced to the study by someone familiar. It also enabled the identification of young people who were known to be aware their parent was dying.

Ten young people from six families agreed to take part; six of the young people had siblings, of whom at least one took part, whilst four young people had no siblings. Research involving families poses the risk of family members recognising each other in written reports even after identifying characteristics have been removed (Forbat and Henderson 2003). By omitting further details about family composition, my aim here is to reduce this risk. Three of the participants were young women; seven were young men. Ages ranged from 13 to 21 years with a median age of 17.

I met each young person individually for a single interview lasting between 25 and 80 minutes. Seven participants chose to be interviewed at home; two young people chose to meet me at a voluntary project, and one young person at their college. Interviews were audio-recorded and transcribed in full. I conducted the analysis using an approach based on Gilligan's voice-centred relational method (Gilligan *et al.* 2003). Multiple readings of each transcript were carried out, with the aim of capturing *what* the young person said about their experience, and *how* they talked about this experience. Doucet and Mauthner (2008) refer to combining the grounded theory question of 'What is happening here?' (Charmaz 2006) with elements of narrative analysis (Reissman 2002) such as an interest in recurring words, imagery, characters and plot.

The 'whats' and 'hows' of young people's narratives were summarised individually and iteratively analysed, facilitating the emergence of initial themes which were added to after reading each account. Individual narratives and emerging themes were shared during regular de-briefings with a research supervisor, enabling on-going reflection and dialogue on analytical processes and decisions. These discussions informed the grouping of themes under broader headings relating to the study's over-arching lines of enquiry. Themes under each heading were refined and defined using constant comparison to develop a schema for organising and interpreting the data. For example, the broad heading of 'resources' encompassed over-arching themes relating to the inter-personal, instrumental, and temporal sources of support young people employed in getting on with their lives.

Talking about the future emerged as a hitherto unrecognised temporal resource deployed by young people who are living with parental terminal illness. This examination of young people's accounts of the future begins by exploring the futures young people envisaged for themselves. I outline the material and social resources young people anticipated having access to, and consider how an imagined future self may function to support young people in making sense of their experiences in the present. I then examine young people's references to parental absence and presence in their narratives of the future, and the moral tales young people tell that enable them to draw on their parent's projected absence as a symbolic resource in getting on with their everyday lives. I illustrate these points using extracts from interviews with young people. All names attributed to young people are pseudonyms.

Young people's narratives of a future self

The majority of young people in the current study had a sense of what they wanted to do with their lives in the future and were able to articulate an account of their future self:

Well I mean, obviously just finishing college, there's stuff I want to do; the apprenticeship I'm looking at and hopefully getting would be great. I mean, it's something I really, really want to do, but if that doesn't work out then I'll have to look at other plans and stuff – something that earns money so I can open up different options. It's like I want to learn to drive, get my first car and to save and see where I go sort of thing. (Luke, 18)

In general, young people did not appear constrained in thinking about the future by an awareness that their parent would no longer be with them. James acknowledged that his plans were being formed in the context of his Mum's prognosis:

There's obviously going to be a lot of big changes coming – not only with the, like the eventual deterioration of my Mum's health, but, you know, I'm possibly going to university and trying to work out what I want to do with my life . . . I feel that everything's open to me, I do. I've got no – I don't feel as though I'm limited, like by whatever's happening in my personal life, so to speak. (James, 17)

Even when they had decided to change their plans in order to accommodate their parent's illness, this was often presented as a temporary decision, to be revised at a suitable point in the future. For example, Elliot had chosen to study at a university in his home town so that he could continue living at home, but he was still intending to move into student accommodation:

I think if I'm honest, I'd always been saying I'll move out either later this year, or at some point when I can. (Elliot, 18)

Elliot mused on the need to balance his wish to get on with his life with the likelihood that his Mum might need support following his Dad's death:

I wouldn't really want to just leave my Mum after her partner's died. Suddenly her partner dies and a couple of months later her son leaves. I think that would be horrible. So I think I will move out in the second year, but I will time it based on when and if he's passed away, probably, but I'm never going to tell her cos she'll feel like she's a burden on me [laughs]. (Elliot, 18)

Although they took care to consider the needs of other family members, young people were generally motivated to continue pursuing their own plans. The awareness that their family situation was going to change significantly in the foreseeable future appeared to enable young people to keep sight of their aspirations, rather than triggering a breach in their biographical narrative.

Overall, young people's narratives of the self in the present and the future were closely woven threads, and often intertwined to add meaning and purpose to their accounts of living with parental terminal illness:

It's made me realise that, no matter what you do and that, nothing's going to be perfect and you've just got to keep trying; don't give up really. Just cos one thing doesn't work, it doesn't mean the next isn't going to. (Dan, 16)

The troubles Dan was experiencing in the present strengthened his resolve to succeed in what he wanted to achieve in the future. In Luke's account, he aspired to a future in which he goes 'from strength to strength', and this gave him the determination to focus on his own needs in the present:

I mean obviously I'm eighteen, so my life's properly beginning sort of thing. So no matter what's happening, I've kind of still got to focus on myself at times as well otherwise I'm just going to, I suppose fall behind, and then I'll have nothing to spring off. I'll just, rather

than going from strength to strength, I'll go from negative to negative, which will put me in no kind of position to move forward – That wouldn't be good. (Luke, 18)

One account that appeared to provide an exception to the interpretation of present and future narratives as mutually reinforcing was that of Jay. Jay had experienced numerous challenges over the course of his life, and as a result he had little in the way of resources with which to build a positive future. He summed up his life as follows:

It's been bad from the start cos my education has been bad from the start, my family problems have been bad from the start, the money problem has been bad from the start. (Jay, 17)

Jay struggled to articulate a future for himself:

I think if my Mum's ill, what if she's not going to make it that long? You know, I've got to use this last year, what if I fail? How am I going to get a job? What job am I going to get? Am I ever going to get married? Am I ever going to have a family? (Jay, 17)

Jay's uncertainty about the future was not only linked to his Mum's prognosis, but also to the difficulties he had encountered since his early years. Jay's account of his life to date provided him with little sense of how he might structure future events, and he was unable to construct a coherent future narrative to help him make sense of the present, leaving him with a series of troubling questions.

It appears that young people who are able to envisage a future for themselves are more likely to maintain a robust sense of biographical continuity; one that is sufficient to support them in moving beyond the major change represented by their parent's death. Having considered young people's accounts of their future selves, I now examine how young people talk about their parent in the future, and consider how change and continuity are threaded through young people's narratives of the self in relation to a parent who is approaching the end of life.

Shifting relational identities and the present-absent parent

Living with a parent who is not going to be there in the foreseeable future appeared to disrupt the meaning and everyday experience of family for young people; not only in the present, but also in the future. For example, when asked about his future, Dan responded:

Knowing that you're going to have a family at some point but they're not going to know your Mum. They're not going to have a Grandma or anything like that; they're going to be – your kids are going to come up asking what happened to my Mum and everything, and then you're going to have to tell them. (Dan, 16)

For Dan, the meaning of family as an on-going narrative transmitted across generations was disrupted by the anticipated death of his Mum. Dan imagined that, through her absence, his Mum would continue to have a tangible effect on him and his family in the future, thus attributing her with a presence in his everyday life that extended beyond her death.

Some young people appeared to envisage their parent as absent when they were still present in order to begin exploring changes in relational identities and future experiences of family in this context. Dan provided a particular example of the process of foreshadowing:

Other people think like, 'When am I going to send my Mum into care?' and, 'I can still look after her' and everything like that. You're thinking, 'Well I don't get a choice about that. My Mum's going to be gone earlier than any of yours'. (Dan, 16)

Imagining the ill parent as absent appeared to function as a form of rehearsal for a future in which the parent would no longer be there, and enabled the young person to begin the process of making sense of anticipated changes in their own lives. The shifting relational identities of parent and child in looking towards the future were vividly articulated by Lauren:

When we were growing up, there was always a safety net. Mum was always the safety net, you know. Whereas now I feel like – up until she was really ill, I still felt, not like a child, but like I could be a child. But now it feels like a change. It feels like I'm not a child any more. Not that I've got to fend for myself, but like I don't have that safety net any more. (Lauren, 21)

Lauren described experiencing the absence of the safety net her Mum represented whilst her Mum was still present in her life. The practice of experiencing the parent as absent when they are still present can be seen as different from, albeit a mirror of, the material, emotional and symbolic practices that sustain a presence for the deceased when they are absent.

The facility to hold both the present and the absent parent in mind and to move imaginatively between states of parental presence and absence may be an enabling factor for young people who are living with dying. As such, the forms and functions of parental presence-absence in the lives of young people with a parent at the end of life are worth further investigation.

Drawing on parental absence to tell a moral tale

One way in which the present-absent parent appeared to function in young people's biographical narratives was in lending moral weight to young people's accounts of the future. Research has shown that being able to stake a claim on a functional family narrative, in which their parent cares *about* them even if they are not always able to care *for* them, is important for young people in difficult circumstances (Backett-Milburn *et al.* 2008, Wilson *et al.* 2012). Young people in the current study sometimes sought to reclaim a moral tale of family and to present themselves in a moral light through paying close attention to their parent's perceived wishes. Young people's biographical narratives were sometimes bolstered by the suggestion they were fulfilling their parent's wishes by re-claiming the future for themselves. For example, Ellie stated:

I've just thought where I'm going to be in the future, and if I'm going to stay at home looking after my Mum, or am I going to get a job and all that? But I've thought about it like, I will go on with my life, cos that's what my Mum will want. She'll want me to go and live my life and go and get a job and all that. (Ellie, 16)

The understanding that they will be acting in accordance with their parent's wishes, even though their parent will no longer be present, lent support to young people's decision-making with regard to the future. Lauren explained her decision to return to university the following year:

I'm going to go back next September because I've made a promise. I don't know how easy it's going to be to get started again – but I'll finish it now for Mum . . . I'll do university because I've promised her. She always wanted me to do that. (Lauren, 21)

In these examples, young people draw on their parent's suggestion that they continue to live their lives as a form of memorial to their parent's absence in the future. In other accounts, young people described their own planned acts of commemoration:

I'd always wanted to climb mountains with [Dad], but it's encouraged me now to climb even more. Like he always wanted to climb Munros, and he's only ever got to climb one,

and it was the last mountain we ever climbed, and yeah, that's something that's been quite emotional for us. I'm going to climb all of the rest of them if I have that much money in my life – cos it was something we really loved doing and really bonded through, so it's a way of carrying that forward into the future. (Elliot, 18)

Elliot's plan to carry his relationship with his Dad 'forward into the future' by doing an activity they enjoyed together demonstrates the emergence of a strategy for maintaining continuing bonds with a parent prior to their absence through death.

These accounts illustrate how young people begin to experiment with notions of parental absence when they are living with a parent who is dying. Young people displayed a capacity to move imaginatively between states of parental absence and presence, blurring the boundaries such that they are less absolute categories and more relative positions, which are not mutually exclusive. It is possible that the practice of re-locating their parent along the continuum of presence-absence while they are still living may facilitate young people getting on with their everyday lives in the present, and may help to develop a moral framework for structuring their accounts of the future.

Discussion

This paper contributes to a growing sociological literature on 'family troubles', which seeks to interrogate changes and challenges in family lives, and to examine why some changes are defined as troubling, how, and by whom (Morgan 2019, Ribbens McCarthy *et al.* 2018). It is acknowledged that living with a parent who has a terminal illness is likely to be troubling for young people, but rather than setting out with a presumption of damage, the current study paid careful attention to how young people themselves talk about their everyday lives with a parent who is dying and the resources young people employ to minimise harm. In drawing attention to the future as a temporal resource young people draw on, I have identified adaptive practices of maintaining biographical continuity and relational identities, alongside references to disruptive change.

Smart (2006: 155) suggests that the construction of a biographical narrative enables children to 'stand outside' of and reflexively evaluate their experiences. She argues that in making sense of the past, children develop the capacity to apply their understanding to future events, such that narratives provide a means of structuring future experiences. In this paper, I explore the notion that the meaning-making potential of narrative is not one-directional and that just as accounts of the present may help young people make sense of the future, so may accounts of the future act as a resource for young people to draw on in making sense of the present.

In opting to construct a future for themselves based on normative assumptions of progress towards adulthood such as leaving home and getting a job, most young people in the current study actively side-stepped a trajectory in which their future lives were blighted by parental terminal illness. Furthermore, in grounding their future biographical narratives in the acquisition of material and social resources, young people gained something to work towards, giving meaning and a sense of purpose to their everyday lives in the present beyond the experience of living with a parent who was dying.

Some of the young people had temporarily suspended plans to leave home for the duration of their parent's illness, but anticipated continuing to move towards this goal beyond their parent's death. It appears that young people's accounts of everyday life did not, therefore, wholly endorse an interpretation of the experience of life-limiting illness as a biographical disruption (Bury 1982). Although young people were dealing with uncertainty, change and significant

loss in their family lives, their thoughts about the future did not appear fundamentally altered by living with a parent who was dying. Instead, recognising that the future contained their parent's death appeared to reinforce young people's own sense of biographical continuity, consolidating their plans for the future and giving meaning to the present.

Reflecting on Jay's experience, it is apparent that young people who lack the material and social resources to develop a coherent narrative of the future may find it significantly more difficult to make sense of their everyday lives in the present, further demonstrating the value of the future as a resource for young people to draw on when they are living with a parent who is dying. The lack of means with which to construct a future narrative appears to be a factor in amplifying the troubles that everyday life with a parent at the end of life may bring.

It has been noted that living with a parent who is not going to be there in the foreseeable future disrupts the meaning and everyday experience of family for young people (Turner and Almack 2019). This paper further illuminates the re-configuration of relational identities that takes place in families prior to a parent's death. It appears that young people begin to prepare for the loss of a parent by imagining them as absent while they are still present. I suggest that the *present-absent* parent functions as a symbolic resource for young people who are living with parental terminal illness, enabling them to rehearse anticipated experiences of parental loss and to identify ways of maintaining a relationship with their parent beyond death. This suggests that relational experiences of the dead as exemplified by Maddrell (2013) may begin prior to bereavement in response to living with dying, and may facilitate the process of continuing bonds (Klass *et al.* 1996).

For some young people, the reassurance that their parent had endorsed the plans they intended to carry out in their absence enabled them to re-stake a moral claim on their own future. The accounts of two of the young women in the study, Ellie and Lauren, gave some indication of the emotional labour undertaken by terminally ill mothers in continuing to offer encouragement and support to their children. Research indicates that maintaining the moral and relational identity of being a 'good' mother is crucial to women facing life-limiting illness (Elmberger *et al.* 2005, Wilson 2007). In striving to meet their moral responsibilities, these mothers also enabled their daughters to develop a moral tale in which Ellie and Lauren were 'doing the right thing' by shifting attention to their own futures. Other young people planned to 'do' continuing bonds through adopting aspects of their parent's values and ambitions, illustrating how internalised connections to the deceased noted by Clabburn *et al.* (2019) may be initiated prior to a parent's death.

It is acknowledged that these findings may be limited by the small sample of young people, all of whom were in contact with services and willing to talk about their experiences. Many young people do not access specialist services when a parent is dying, and instead may be 'hidden in plain sight' in schools, workplaces and communities. The experiences of young people who do not receive formal support, or who do not want to talk about their family circumstances may differ. A larger sample of young people may also have enabled the potential influence of factors such as gender, age and family composition to be scrutinised. Nevertheless, the voices of young people who are prospectively encountering a parent's illness and death are a strength of the study. Involving young people in research when a parent is dying is challenging (Turner and Almack 2017), leading some studies to rely instead on reporting retrospective experiences of young people post-bereavement, and sometimes much later in life.

In considering the implications for practitioners in contact with young people when a parent is dying, it may be helpful to avoid making the assumption of harm, and instead to create a space in which young people can develop their own accounts of family life. In particular, it may be beneficial to support young people in developing a positive narrative of the future, which may help to ameliorate the effects of living with parental terminal illness in the present.

Conclusion

Ribbens McCarthy (2007) describes how young people's efforts towards sense-making following a bereavement are an example of how young people exercise agency in circumstances often exemplified by a lack of power and loss of control. In constructing a biographical narrative, most young people in the current study were able to present an alternative to the harm story, in which the anticipated trajectory of their lives remained a constant. It appeared that, even though they were facing considerable disruption and loss, young people retained a sense of their own future which was both coherent and purposeful. In connecting present and future selves across the biographical rupture potentially triggered by their parent's death, young people were able to draw on their future selves as a symbolic resource, albeit one which required material and social resources to construct.

The findings also illustrate how young people living with parental terminal illness 'join the dots' between the parent in the present and the parent who will be absent in the foreseeable future. The ability to move imaginatively between states of parental presence and absence appeared to support young people by stimulating new, relational experiences of the absent parent prior to death. These experiences demonstrate that the relational practice of continuing bonds with the deceased may extend prior to bereavement, and may facilitate everyday living in anticipation of significant loss.

Overall, this study suggests that the ability to shape, and the opportunity to express, a future for themselves, albeit one in which their parent will no longer be with them, may enable young people affected by parental terminal illness to adopt ways of being that are helpful to them, both in the present and beyond.

Address for correspondence: Nicola Turner, School of Health Sciences, Queen's Medical Centre, Room 302, B Floor, South Block, Nottingham NG2 7QP, UK.

E-mail: nicola.turner@nottingham.ac.uk

Acknowledgements

I thank the young people who took part in the study; my research supervisor, Professor Kathryn Almack, and the reviewers for their helpful comments.

References

- Andriessen, K., Mowl, J., Lobb, E., Draper, B., *et al.* (2018) "Don't bother about me." The grief and mental health of bereaved adolescents, *Death Studies*, 42, 10, 607–15.
- Backett-Milburn, K., Wilson, S., Bancroft, A. and Cunningham-Burley, S. (2008) Challenging childhoods: young people's accounts of 'getting by' in families with substance use problems, *Childhood*, 15, 4, 461–79.
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, 2, 167–82.
- Bury, M. (1991) The sociology of chronic illness: a review of research and prospects, *Sociology of Health & Illness*, 13, 4, 451–68.
- Charmaz, K.C. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage.
- Claburn, O., Knighting, K., Jack, B. and O'Brien, M. (2019) Continuing bonds with children and bereaved young people: a narrative review, *OMEGA – Journal of Death and Dying*. <https://doi.org/10.1177/0030222819853195>.

- Dalton, L., Rapa, E., Ziebland, S., Rochat, T., *et al.* (2019) Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent, *The Lancet*, 393, 10176, 1164–76.
- Doucet, A. and Mauthner, N. (2008) What can be known and how? Narrated subjects and the listening guide, *Qualitative Research*, 8, 3, 399–409.
- Ellis, S.J., Wakefield, C.E., Antill, G., Burns, M., *et al.* (2016) Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions, *European Journal of Cancer Care*, 26, e12432. <https://doi.org/10.1111/ecc.12432>.
- Elmberger, E., Bolund, C. and Lützn, K. (2005) Experience of dealing with moral responsibility as a mother with cancer, *Nursing Ethics*, 12, 3, 253–62.
- Forbat, L. and Henderson, J. (2003) "Stuck in the middle with you:" the ethics and process of qualitative research with two people in an intimate relationship, *Qualitative Health Research*, 13, 10, 1453–62.
- Franklin, P., Arber, A., Reed, L. and Ream, E. (2019) Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: a qualitative review and thematic synthesis, *Palliative Medicine*, 33, 1, 49–65.
- Gilligan, C., Spencer, R., Weinberg, M. and Bertsch, T. (2003) On the listening guide: a voice-centred relational method. In Camic, P., Rhodes, J. and Yardley, L. (eds) *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design*. Washington: American Psychological Association.
- Greenwood, N. and Mackenzie, A. (2010) Informal caring for stroke survivors: meta-ethnographic review of qualitative literature, *Maturitas*, 66, 3, 268–76.
- Hanna, J.R., Mccaughan, E. and Semple, C.J. (2019) Challenges and support needs of parents and children when a parent is at end of life: a systematic review, *Palliative Medicine*, 33, 8, 1017–44.
- Hansen, D., Sheehan, D., Stephenson, P. and Mayo, M. (2016) Parental relationships beyond the grave: adolescents' descriptions of continued bonds, *Palliative and Supportive Care*, 14, 4, 358–63.
- Jamieson, L. and Hight, G. (2013) Troubling loss? Children's experience of major disruptions in family life. In Ribbens McCarthy, J., Hooper, C. and Gillies, V. (eds) *Family Troubles? Exploring Changes and Challenges in the Family Lives of Children and Young People*. Bristol: The Policy Press, pp. 135–50.
- Klass, D. (2015) Continuing bonds, society, and human experience: family dead, hostile dead, political dead, *OMEGA – Journal of Death and Dying*, 70, 1, 99–117.
- Klass, D., Silverman, P.R. and Nickman, S. (1996) *Continuing Bonds: New Understandings of Grief*. London: Taylor and Francis.
- Locock, L. and Ziebland, S. (2015) Mike Bury: biographical disruption and long-term and other health conditions. In Collyer, F. (ed) *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*. London: Palgrave Macmillan, pp. 582–98.
- Lytje, M. and Dyregrov, A. (2019) The price of loss – a literature review of the psychosocial and health consequences of childhood bereavement, *Bereavement Care*, 38, 1, 13–22.
- Maddrell, A. (2013) Living with the deceased: absence, presence and absence-presence, *Cultural Geographies*, 20, 4, 501–22.
- Maddrell, A. (2016) Mapping grief. A conceptual framework for understanding the spatial dimensions of bereavement, mourning and remembrance, *Social & Cultural Geography*, 17, 2, 166–88.
- Morgan, D.H. (2019) Family troubles, troubling families, and family practices, *Journal of Family Issues*. <https://doi.org/10.1177/0192513X19848799>.
- Morris, J., Turnbull, D., Preen, D., Zajac, I., *et al.* (2018) The psychological, social, and behavioural impact of a parent's cancer on adolescent and young adult offspring aged 10–24 at time of diagnosis: a systematic review, *Journal of Adolescence*, 65, 61–71.
- Pearce, C. (2011) Girl, interrupted: an exploration into the experience of grief following the death of a mother in young women's narratives, *Mortality*, 16, 1, 35–53.
- Penny, A. (2018) Preparing the way: evaluating support for children and young people before the death of someone important to them, The Childhood Bereavement Network. Available at <http://www.childhoodbereavementnetwork.org.uk/media/91314/Preparing-the-way.pdf> (Last accessed 11 November 2019).

- Phillips, F. and Lewis, F. (2015) The adolescent's experience when a parent has advanced cancer: a qualitative inquiry, *Palliative Medicine*, 29, 9, 851–8.
- Rainville, F., Dumont, S., Simard, S. and Savard, M.-H. (2012) Psychological distress among adolescents living with a parent with advanced cancer, *Journal of Psychosocial Oncology*, 30, 5, 519–34.
- Reissman, C.K. (2002) Analysis of personal narratives. In Gubrium, J. and Holstein, J. (eds) *Handbook of Interview Research*. Thousand Oaks: Sage.
- Ribbens McCarthy, J. (2007) 'They all look as if they're coping, but I'm not': the relational power/lessness of 'youth' in responding to experiences of bereavement, *Journal of Youth Studies*, 10, 3, 285–303.
- Ribbens McCarthy, J. and Prokhovnik, R. (2014) Embodied relationality and caring after death, *Body & Society*, 20, 2, 18–43.
- Ribbens McCarthy, J., Hooper, C. and Gillies, V. (2013) Troubling normalities and normal family troubles: diversities, experiences and tensions. In Ribbens McCarthy, J., Hooper, C. and Gillies, V. (eds) *Family Troubles? Exploring Changes and Challenges in the Family Lives of Children and Young People*. Bristol: The Policy Press, pp. 1–21.
- Ribbens McCarthy, J., Gilles, V. and Hooper, C.-A. (2018) Introduction to special section: troubling families, *Sociological Research Online*, 23, 1, 153–9.
- Sheehan, D.K. and Draucker, C.B. (2011) Interaction patterns between parents with advanced cancer and their adolescent children, *Psycho-Oncology*, 20, 10, 1108–15.
- Sheehan, D.K., Mayo, M.M., Christ, G.H., Heim, K., *et al.* (2016) Two worlds: adolescents' strategies for managing life with a parent in hospice, *Palliative & Supportive Care*, 14, 177–86.
- Smart, C. (2006) Children's narratives of post-divorce family life: from individual experience to an ethical disposition, *The Sociological Review*, 54, 1, 155–70.
- Thastum, M., Johansen, M., Gubba, L., Olesen, L., *et al.* (2008) Coping, social relations, and communication: a qualitative exploratory study of children of parents with cancer, *Clinical Child Psychology and Psychiatry*, 13, 1, 123–38.
- Trusson, D., Pilnick, A. and Roy, S. (2016) A new normal? Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer, *Social Science & Medicine*, 151, 121–9.
- Turner, N. (2018) Young people's perspectives on open communication between family members when a parent is dying, *Palliative and Supportive Care*, 16, 4, 414–20.
- Turner, N. and Almack, A. (2017) Recruiting young people to sensitive research: turning the 'wheels within wheels', *International Journal of Social Research Methodology*, 20, 5, 485–97.
- Turner, N. and Almack, K. (2019) Troubling meanings of family and competing moral imperatives in the family lives of young people with a parent who is at the end of life, *Children's Geographies*, 17, 5, 527–38.
- Tyson-Rawson, K. (1996) Relationship and heritage: manifestations of ongoing attachment following father death. In Klass, D. (ed) *Continuing Bonds: New Understandings of Grief*. Philadelphia: Taylor & Francis.
- Walczak, A., McDonald, F., Patterson, P., Dobinson, K., *et al.* (2018) How does parental cancer affect adolescent and young adult offspring? A systematic review, *International Journal of Nursing Studies*, 77, 54–80.
- Wilson, S. (2007) 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption, *Sociology of Health and Illness*, 29, 4, 610–26.
- Wilson, S., Cunningham-Burley, S., Bancroft, A. and Backett-Milburn, K. (2012) The consequences of love: young people and family practices in difficult circumstances, *The Sociological Review*, 60, 1, 110–28.