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

This article draws on a narrative study of young people with a parent who is at the end of life to examine how family lives are troubled by life-limiting parental illness. Young people struggled to reconcile the physical and emotional absence of family members with meanings of ‘family’; the extent to which young people could rely on family to ‘be there’ in these troubling circumstances was of practical, emotional and moral significance. Our discussion is situated in the context of an English end of life care policy predicated on the ideal of a good death as one that takes place at home accompanied by family members. We explore how the shift away from family as a site for nurturing children towards family as a space to care for the dying is experienced by young people, and consider how these competing moral imperatives are negotiated through relational practices of care.

Keywords: young people, family, care, child-adult relations, moral geography

Introduction

The anticipated death of a parent due to a life-limiting illness is generally perceived as an extraordinary change in the life of a young person, and one that is understood as profoundly troubling. However, little is known about young people’s everyday experiences of living with dying. Research studies of young people with a parent who is at the end of life have tended to focus on the negative outcomes of advanced parental illness for young people (Huizinga et al. 2011; Rainville et al. 2012) and on strategies for ‘coping’ (Maynard et al. 2013; Thastum et al. 2008). A limitation of this research is that it considers the young person in isolation, often drawing on models of risk and resilience to conceptualise young people’s experiences and responses to family ‘troubles’ (Ribbens McCarthy, Hooper and Gillies 2013) as dependent on attributes located within the individual. Less attention has been paid to relational aspects of young people's everyday lives, or to the broader social and spatial context in which their experiences of living with dying are situated.

Yet the concept of 'family' as both a physical and a psychosocial locus of care forms a cornerstone of policy and practice in end of life care in England. Research indicates that family relationships matter to people who are approaching the end of life (Gott et al. 2004; Solomon and Hansen 2015). The familiarity, reassurance and comfort that can be found in the presence of family members are often cited as factors in achieving a 'good death' (Clark 2002). Furthermore, the support provided by family and friends is an integral part of health and social care provision. Research produced by Carers UK in 2015 calculated that the economic value of care provided by family members is £132 billion per year; close to the total annual cost of health spending (Buckner and Yeandle 2015). Families, and the care provided by family members throughout the illness trajectory, are therefore regarded as important in optimising individual experiences of dying and death. However, there has been little interrogation of what is meant by 'family' in this context, or of the ways in which proximity to death impacts on all those who are living alongside someone who is approaching the end of life.

In this paper, we report on an exploratory study of young people's experiences of living with a parent who is at the end of life. We begin by considering how notions of home, family and care converge and are conflated in the social narrative of a good death, and we discuss how the good death discourse influences everyday debates and decisions about the 'proper' thing to do in families when someone is dying. We then provide an outline of our study, in which we set out to investigate the routines and practices that constitute everyday family life for young people when a parent is dying and their experiences of both giving and receiving care in this context.

In our discussion of the study findings, we argue that young people's experiences of family life are both informed and challenged by the moral tale of a good death as one that takes place in the home accompanied by family members. We explore how the presence/absence of significant others from the material and emotional space of 'home' affects the experience of life-limiting parental illness for young people, and we examine how young people respond to the inherent moral expectations of others and themselves to be present and to support their parent on their approach to death. In doing so, we aim to elaborate on how the experience of advanced parental illness 'troubles' everyday family life for young people, and to illuminate how young people encounter and ameliorate troubling 'changes and challenges' (Ribbens McCarthy, Hooper and Gillies 2013) to 'family' through relational practices of care.

Family, care and the 'good death'

Research suggesting that most people would prefer to die at home (e.g. Higginson and Sen-Gupta 2000) has been used to underpin a policy approach to end of life care in England in which the family is central to enabling people to die 'in the place of their choice' (Department of Health 2008, 107). The importance of achieving a 'good death' has therefore become influential in defining 'home' as a space for the delivery of end of life care and in determining how family relationships are viewed and understood when someone is dying. However, a closer scrutiny of the research indicates that preference with regard to place of death is more nuanced than earlier studies suggest, and may vary according to factors such as illness progression (Gomes et al. 2013), ethnic background (Seymour et al. 2007) and the availability and attitudes of family members towards providing care at home (Gott et al. 2004).

Pollock (2015) raises a number of concerns with the survey methodology often used to establish preferred place of death; notably that public surveys mostly capture the views of people who are healthy, many of whom have little prior knowledge or experience of life-limiting illness and death, and may have limited awareness of what dying at home might entail. Furthermore, public surveys rarely report on the number of people who do not express a preference, or who do not have a preferred pace of death (Hoare et al., 2015). The overall picture with regard to home as a preferred place of death is therefore difficult to ascertain. Nevertheless, eight years on from the publication of the End of Life Care Strategy (Department of Health 2008), Deaths in Usual Place of Residence (DiUPR) remains a key proxy measure of quality in end of life care.

Home as defined by the DiUPR measure represents a physical space distinct from a hospital or other health care setting. However, ‘home’ can also be understood as a psychosocial space; idealised as the locus of our most intimate relationships, closely bound up with notions of family, belonging and sense of self (Blunt and Varley 2004; Mallett 2004). The notion of home as a psychosocial space is inherent in the emphasis on accompaniment within the good death discourse. Deaths that take place at home unaccompanied by family or friends are generally characterised as ‘bad’ and as indicative of troubling changes in family and wider social relationships (Caswell and O’Connor 2015). The conflation of dying at home and the presence of family with the moral ideal of a good death risks promoting ‘a sense of guilt and failure if death occurs elsewhere’ (Pollock 2015, 3). Such negative consequences are the potential legacy of family members (including young people) who have not been present to enable a home death to take place. The moral stakes for family members who are unwilling or unable to offer their support are therefore raised by the importance of family presence to the provision of ‘good’ end of life care.

The good death discourse that informs individual decisions about end of life care may therefore privilege the option to remain at home, potentially transforming the notion of choice with regard to place of death into a ‘de facto obligation’ (Pollock 2015, 3). Achieving a home death inevitably impacts on family members, especially those who are co-resident with the person at the end of life. Research suggests that individuals often take into account the presence of family members in making decisions about end of life care (Gomes and Higginson 2006), although this process is far from unambiguous or straightforward. For some, the reassurance that family members are close at hand may support a decision to remain at home, whilst others may be more influenced by concerns about being a burden on their family (Cox et al. 2013; Gott et al. 2004). These findings suggest that the conflation of spatial and psychosocial meanings of home and family in the good death discourse may be a potential source of tension between family members. Further research could help to explore how this tension is manifested and resolved in and through everyday family life when someone is dying.

So far, we have suggested that end of life policy discourse, with its emphasis on promoting home as a place of death, is predicated on an enduring ideal of a good death which confers an obligation on family members to be present and provide care for the dying. Next, we introduce a qualitative study in which we aimed to explore the family lives of young people with a parent who is at the end of life, and to investigate young people’s involvement in family care in this context.

Caring to the End: Exploring the family lives of young people with a parent who is at the end of life

The importance of family care to end of life care provision has been reflected by a growing body of research examining the roles, responsibilities and experiences of family members in delivering care at home to people approaching the end of life. Researchers have considered the process of becoming a carer (Smith 2009), the support needs of carers (Morris 2015), and the efficacy of interventions to support carers (Harding et al. 2011). However, a significant part of this research adopts an approach that assumes a dyadic relationship between a ‘carer’ and a ‘cared for’ (Molyneaux et al. 2011). There has been less emphasis on the study of care at the level of ‘family’, and on the everyday routines and practices that constitute family life in the context of providing end of life care for a family member (Broom and Kirby 2013; Ellis 2013).

Furthermore, the majority of this research has focussed on the experiences of adult carers, often the partners or adult children of the person approaching the end of life. This is not surprising given the demographic profile of people who die. Figures produced by the National End of Life Care Programme (2010) indicate that 58.4% of all male deaths and 74.4% of all female deaths occurred in people aged over 75. Nevertheless, it is estimated that 5% of young people experience the death of a parent by the age of 16 (Parsons 2011), and 24% of all adults with cancer have children under the age of 18 (Semple and McCance 2010). The experience of living with a parent who has a life-limiting illness is therefore not wholly uncommon for young people in the England, and merits further investigation.

The *Caring to the End* study was based on individual, semi-structured interviews with ten young people (age 13-21) and five significant others who were nominated by a young person (four parents and one partner of a young person). Five of the young people took part in the study along with a sibling, therefore the study participants were drawn from six families in total. Not all of the young people nominated a significant other; some reported that they were reluctant to approach their parent because the parent was too ill to take part. Others struggled to identify anyone whom they felt comfortable to approach. Characteristics of the study participants are outlined in Table 1. We have chosen to present information about study participants in a way that does not explicitly reveal the relationships between the young people and their significant others. This decision has been taken to better protect the identities of participants. One issue with studies involving multiple family members is that individuals and families may be recognisable in research reports, even after any identifying characteristics have been removed (Forbat and Henderson, 2003). By not providing more detailed information about family composition, the aim is to reduce this risk.

Table 1: Characteristics of the young people included in the study (n = 10)

[Table 1 near here]

All of the young people had a parent who had been identified as being at the end of life; this is commonly defined as being ‘likely to die in the next twelve months’ (NCPC 2011, 4). All were aware that their parent’s prognosis was limited, albeit we acknowledged that research indicates it is not uncommon for individuals receiving end of life care and their family members to move in and out of awareness, or to have fluctuating degrees of awareness of prognosis (Richards et al. 2013). Prior approval for the study was granted by an NHS Research Ethics Committee.

Young people were recruited as participants via practitioners working at one of eight research sites comprising three young carers’ projects, two NHS end of life care service providers and three hospices. The study sites were selected because they were likely to be in contact with young people who met the study criteria. The use of multiple sites increased the prospect of identifying eligible young people within the study time frame.

The decision to approach young people via a practitioner who was already in contact with them and/or their family was introduced as a measure to mitigate the potential for distress. In line with Notko et al. (2013), we viewed practitioners as professionals who could act as ‘safety nets’, and who would better enable a sensitive introduction to the research context. The sample size of ten young people is in line with other qualitative studies of young people’s experiences of advanced parental illness (Melcher, 2015; Phillips, 2015), and reflects the difficulties of recruiting young people to exploratory research on death and dying. Further discussion of the ethical and practical issues we encountered during study recruitment can be found elsewhere (Author Ref, 2016).

The research interviews explored the everyday processes and practices that constitute family life for young people, their experiences of caring and being cared for, and their thoughts about their own lives both now and in the future. Young people’s accounts were transcribed and analysed using the voice-centred relational method (Gilligan et al. 2003), a narrative approach involving multiple readings of a transcript to illuminate different aspects of the young person’s account. The narratives of family members were used to support a multiple perspectives analysis of how young people understood and experienced the relational constructs of family and care (Ribbens McCarthy, Holland and Gillies 2003). The multiple perspectives analysis involved reading the accounts of young people alongside those of their significant others in order to identify similarities and differences in how the concepts of family and care were manifested and described, and how family life was constructed by young people *in relation* to those who are important to them.

The presence or absence of significant others from the physical and psychosocial space of home emerged as significant in young people’s accounts of living with a parent who is at the end of life. This was most frequently expressed through references to closeness and care. In the following discussion of the research findings, particular attention is paid to how the presence/absence of others from the home space impacted on the meaning and practice of family for young people, and how young people responded to the moral imperative to 'be there' to accompany their parent as they approached the end of life. All names attributed to young people are pseudonyms.

Closeness, care and 'being there'

The use of 'closeness' as both a spatial and an emotional variable to describe family relationships was a recurring feature of young people's accounts. The geographical proximity of a relative was a factor in enabling them to have a regular presence in the young person's home and family life:

> *My aunty lives down the street…she phones up, she rings up and like, just pops in and then, popping in and out really.* *(James, 17)*

> *The only other relative that lives near is my Mum's mother who has been very helpful. Grandma is cooking up meals for him every so often, putting them in little Tupperware boxes to freeze.* *(Elliot, 18)*

Davies (2012) writes about the importance of 'seeing' family members as a relational practice that enables children to gain knowledge of and feel connected to others, but here it appears there is a more pragmatic value attached to proximity in that it enables others to provide emotional and practical support to the young person and to family members in the home. Closeness as a spatial variable is therefore important in understanding how young people assess family relationships when a parent is at the end of life in that it influences the extent to which individuals are physically available to 'do family' (Morgan 1996) through the practice of care.

However, as Milligan and Wiles (2010) point out, proximity equates to more than geographical closeness in that those who are physically distant can be socially and emotionally proximate. The young people in our study also applied the notion of closeness to describe the emotional bonds between family members; in particular, bonds that had been tested but proved resilient in the face of parental illness. For example, Luke described his family as 'pretty strong', but went on to explain how relationships between family members had been strained:

> *Obviously with everything with my Mum we've been through a lot which, I suppose in certain senses has brought us closer as a family but then in others, sort of a bit further away...I suppose, if you thought of it like a string, all the time it's a lot thinner than it normally would be. It's like, normally it's probably say that thick and you can take a lot more, but cos of everything that's going on in our lives it's - it takes a lot less.* *(Luke, 18)*

The association of family with both physical and relational proximity is particularly pertinent for this group of young people as it evokes the wider social expectation that family members will rally round to provide care and support for a person who is dying. As we have discussed, spatial and emotional interpretations of closeness are conflated by the moral narrative of a 'proper' way to do family at the end of life, and this was often reflected in young people's accounts. Family members who were physically present in young people's everyday lives tended to be presented as emotionally close, whilst those who were physically absent from the home were sometimes described as emotionally distant; in particular as *not caring*. In the following extracts, Luke and Dan are talking about extended family members who do not live nearby:

> *I get the impression that they don't care that much. They've never been overly close...Before the whole bone cancer thing she had breast cancer so there was always that, which you thought would bring them a bit more in and get them a bit more involved, but it never really did.* *(Luke, 18)*

> *You just get the opinion that they don't really care. Her sister just, hardly rings and never comes. Came for the first time in about three years yesterday.*
> *(Dan, 16)*

For Luke and Dan, the physical absence of family members whom they expected to rally round was indicative of their emotional distance. Conversely, the willingness of others to travel in order to be present in the home to offer support was presented by Lauren as an indicator of what she described as her 'close extended family':

> *They've all got hearts of gold and they will be there for you if you need them... I know that if I have a problem I can text my cousin and she'd, if she needed to be here, she'd be here, however long it takes.* *(Lauren, 21)*

Closeness and care were therefore inter-related concepts applied by young people to describe family and captured by the over-arching concept of 'being there'. The emphasis on family members being there (or not being there) encapsulated both the physical and emotional proximity associated with the meaning of family for young people with a parent who is at the end of life, and engendered a sense of family closing ranks to consolidate its resources in the face of the existential challenge posed by parental illness.

Young people's allusions to family members being there echoed the sense of togetherness and belonging frequently cited and often taken for granted in everyday understandings of family life (Ribbens McCarthy 2012). The importance of being there has also been discussed in relation to conceptualising familial roles and responsibilities such as grandparenting (Mason, May and Clarke 2007) and working parenthood (Harden et al. 2013). The significance of physical and emotional presence in defining what it means to be part of a family is therefore well documented in the research literature (Williams, 2004). However, the accounts of young people in our study suggest that the notion of being there may be imbued with particular significance by young people during troubling times.

As the previous quotes from Luke and Dan illustrate, the inability or refusal of relatives to be there was keenly felt by young people and was not only interpreted as a lack of care, but was also depicted as a moral breach of what might reasonably be expected from people defined as family. The lack of contact from friends was referred to less frequently, and in terms that suggested it was a legitimate response to the young person's difficult circumstances:

> *I think one of my mates really struggles. He just, he sometimes comes round and he just, he's a bit stuck really, what he says. He doesn't know whether to say anything or not, or whether it would upset my Mum and stuff like that.*
> *(Dan, 16)*

Dan's quote implies an understanding that friends may not always feel comfortable to be there for young people. However, the meaning of family appeared to include a necessary sense of presence and a willingness to make oneself available to another who is in need. Young people recognised the limitations imposed by geographical distance on the ability of some family members to be physically present, but they expected them to at least retain a virtual presence, keeping in touch by regular telephone calls or on social media. In the following extracts, Elliot and Lauren are talking about relatives who have moved away:

> *She's never really, despite the fact that she's been so far away; she's never been an absent presence in the immediate family. It always kind of feels like she's there still, because she's always calling us every other day. (Elliot, 18)*

> *We're friends on Facebook and we chat and that. It's just I see pictures of him, and he sees pictures of me, and it's just nice to know that he's there.*
> *(Lauren, 21)*

These extracts illustrate how the practice of caring for another does not depend on geographical proximity since care can be given and received across physical space (Milligan and Wiles 2010). What appears to be important to young people in difficult circumstances is the experience of family members as relationally aligned; or ‘on their side’ (Gottzén and Sandberg *forthcoming*).

As well as alluding to the support given by others, some young people acknowledged the implicit reciprocity of being there in relation to family by describing how they wanted to be there for other family members:

> *I kind of feel like I want - it’s not necessarily I want to be, I feel like I need to be there for both of them, my Mum and my Dad.* *(Elliot, 18)*

> *I suppose I’ve been there for my brothers where my Mum and Dad couldn’t have been.* *(Matt, 20)*

In constructing the meaning of family through notions of presence, support and solidarity, young people with a parent who is at the end of life reflected Finch & Mason’s (1993) observation; ‘The least you can do for your relatives is to rally round in a crisis – this seems to be the touchstone of whether a family can really be said to ‘exist’’ (1993, 33). This expectation appeared to underpin the accounts of young people living with a parent who is at the end of life, and took on a particular, moral significance when there was limited evidence of this happening in their everyday lives.

Whilst it is likely that the absence of extended family would not have been as keenly felt by young people in less difficult circumstances, the physical and emotional absence of family members in this study was something young people struggled to reconcile with the meaning of family. The heightened awareness of what family members *should* be doing in terms of *being there* is augmented by a social narrative of accompanied dying at home as essential to the fulfilment of a good death. Home is therefore reimagined as a moral space in which the significance of home and family as interconnected sites for the formation and enactment of moral identities is reinforced (Hall 2016). In their accounts of everyday family life, young people were often engaged in the telling of a moral tale, in which they explored the legitimacy of their family's claim on being a proper family by assessing the extent to which family members (including themselves) met the responsibility to be there.

Moral tales of being there

The idea that family members *should* rally round to offer support and comfort, whilst strongly endorsed, was not always realised in young people's everyday lives. Most young people made reference to family members who had failed to be there:

> *My Dad, he's not like usually around, but my Gran helps my Mum a lot.*
>
> *(Ellie, 16)*

> *They would never come down to visit us. I think until now they only actually came down about three times, and we've gone up, in my life time, probably around twenty, which is funny cos they have more money than us.*
>
> *(Elliot, 18)*

Elliot's quote implies a moral judgement that family members were doing the *wrong* thing by not visiting, even though they had the resources to act in the proper manner. The absence of 'legitimate excuses' (Finch and Mason 1993) sometimes led young people to reject their relative's claim on a moral identity. For example, Jay described how his uncle had been reluctant to offer any support, and had only made himself available when he felt bound by a sense of obligation to his nephew:

> *That was my uncle's attitude, where my friends' attitude; even though he's a friend we have to help him. They don't have to help me but they still helped me...I'd say having bad family members, like people from my Mum's side like my uncle, people like that [has been difficult].* *(Jay, 17)*

Jay’s account led him to the conclusion that his uncle was a ‘bad family member’, thus demonstrating the struggle some young people experienced in stitching together a narrative of a proper family. Ellie constructed a moral tale of family by emphasising that her Gran was available to do the right thing even though her Dad was not. These extracts resonate with the findings of a study by Wilson et al. (2012) of young people affected by parental substance use, who often worked hard through their accounts of everyday family life to stake a claim on a functional family narrative of closeness and care. The authors attribute young people’s efforts to sustain a moral tale of family to ‘the sense of loss and threat posed to their ontological security by serious problems in their family of origin (2012, 124). The threatened loss of ontological security may have particular significance for young people who are facing the death of a parent. In this context, it appears that the construction of a morally sustainable narrative of family involves the framing of young people’s everyday experiences in a moral discourse of achieving a good death through being there for family at the end of life.

The dilemma of creating a moral tale of family may be further exacerbated by the increased vulnerability of a parent as they approach death. The contemporary tendency for death to be constructed as an extraordinary crisis (Ellis 2013) affords the dying a particular status, in which they are regarded as reprieved of the responsibilities attached to other social roles (Seale 1998). Even though dying people themselves may continue to try and meet the obligations associated with their existing relational identities, being near the end of life is generally perceived as warranting a focus on the practical, relational and personal tasks relevant to the individual process of dying (Emanuel, Bennett and Richardson 2007).

In a study of families facing change, Ribbens McCarthy, Edwards and Gillies (2000) suggest that in responding to family troubles there is a discursively apparent moral imperative to put the needs of children first. They report that this ‘unquestioned and unquestionable imperative’ (2000, 789) was subscribed to by all of the parents interviewed for their study, at least to some degree. However, when a parent is at the end of life, the actions of young people and family members appear to be shaped by a competing moral imperative to attend to the needs of the dying person. This shift away from family as a site for nurturing children towards family as a space to care for the dying may begin many years before the point of death; for example, when a life-limiting illness is first diagnosed.

Young people in the current study appeared to recognise that the moral compass of family life had shifted as a consequence of their parent’s deteriorating health, and that the everyday doing of family had been troubled by a change in family priorities. For example, although parents interviewed for the study often spoke of being there for their children, young people did not wholly endorse their parents’ accounts of being there for them:

> *My Dad has two things on his mind. There’s thinking about Mum and there’s thinking about his mum, so it’s, yeah, his mind is in two places and then - and then he realises he’s got kids and then he realises, ‘Oh I haven’t got time for them. What do I do?’* *(Dan, 16)*

> *We’re all doing our separate things during the day really. I could be sitting here and listening to music all day. It doesn’t bother me not talking to anyone. Dad is always like washing up or messing around trying to do the stuff that he should be doing, like helping my Mum and that.* *(Joe, 13)*

When talking about parental absence, young people often alluded to changes in family practices and actively engaged in working out new ways of doing family that took into consideration their parent’s need for care. For example, Lauren’s narrative provided a particularly striking example of the shift in moral obligations in her relationship with her Mum:

> *When we were growing up, there was always a safety net. Mum was always the safety net, you know. Whenever I had a problem or I didn't know what to do or how to do it, she always did, or if she didn't she soon would. 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's account illustrates how she had responded to the growing awareness that her Mum was no longer able to meet her needs by 'turning the tables' and being there for her Mum:

> *Well I go to all of her appointments with her...and with the chemos and all that I was always there... I'd go with her every single time cos I wanted to. Just cos I know if the tables were turned she'd be there for me.* *(Lauren, 21)*

For some young people, sustaining a moral narrative of family as a parent approached death therefore entailed caring for their parent until the end, and thereby fulfilling the expectations associated with the good death discourse. In this way, young people were able to demonstrate that their family was responding in the proper manner to the approaching death of a parent, albeit they were no longer able to meet the moral imperative for family to put the needs of children first.

Wilson's (2013) account of the absence of expected family practices for some young people affected by parental substance misuse illustrates how a young person's experience of loss may be compounded by a sense of having breached their own moral obligation to family by not being there for their parent. This suggests that a young person's moral self may be at stake if they are unable to sustain a moral tale of closeness and care between family members. Stepping in to provide care for a parent whose ability to care for them had become compromised by their illness therefore served the dual purpose of maintaining the family’s moral reputation and preserving the young person’s own moral identity.

The inter-weaving of moral narratives in the everyday family lives of young people with a parent who is at the end of life was therefore complex and sometimes challenging. As an example of the unpicking of this moral tapestry, we have discussed how the moral obligation of family members to be there when a parent is at the end of life is experienced as troubling for some young people, in that the absence of family members transgressed the narrative of a good death. Conversely, being able to cite instances when family members had been there, or where young people had been there for others, enabled young people to bolster their sense of belonging to a proper family and to demonstrate a moral tale of family doing the right thing in the difficult circumstances engendered by parental illness.

For young people who are living with a parent who is at the end of life, the weaving of a moral tale appeared to involve balancing the moral imperative for parents to prioritise the needs of their children with an alternative moral imperative for family members to care for the dying. We suggest that it is the offsetting of these moral obligations in and through the routines and practices of everyday life that underpins family and shapes the experiences of young people in these changing and challenging circumstances.

Conclusion

In this paper, we have drawn on an empirical study of young people’s accounts of living with a parent who is at the end of life to describe how the construction of ‘family’ is characterised by notions of presence, closeness and care; meanings that were informed by everyday experiences of absence, change and loss. For young people in our study, home represented a physical and a psychosocial space where they were doubly troubled by, on the one hand living with dying, and on the other by belonging to a family that had fallen short of expectations of family members being there. We have described how home as a place of care *by* and *for* family members is underpinned by the social narrative of a good death, and we have explored how the good death discourse interprets and promotes home as a moral space through the construction of a proper way for family members to respond to the presence of dying.

Recent research on the dynamics of family troubles across a diverse range of contexts has raised important questions about how 'troubles' are defined, by whom, and when it may be necessary to intervene to prevent or minimise the impact of family troubles on those who may be adversely affected by their experiences of disruption and change (Ribbens McCarthy, Hooper and Gillies 2013). Central to this debate is the recognition that all families experience troubles; even the event of a death is (at least statistically) a 'normal' part of family life (Ribbens McCarthy 2007). What this paper adds to the debate concerns the extent to which the life-limiting illness of a parent represents 'a disruption of a *different* kind' (2007, 288) for young people.

We have argued that the shift away from family as a site for nurturing children towards family as a space to care for the dying is particularly significant for young people when a parent is approaching the end of life. Although they may continue to care for their children, parents with advanced illness require more care from family members as their health deteriorates. The discourse of a good death ensures that family members are oriented towards meeting the needs of the ill parent in order to avoid the sense of having failed to fulfil a moral duty. Some young people appeared to recognise that the capacity for family to meet their needs was undermined as a consequence, and many responded by taking on more responsibility to provide care for family members and for themselves. The changing moral imperative for family when a parent is dying is therefore understood, experienced and negotiated by young people through relational practices of care.

The shift in the moral dynamics of family when a parent is at the end of life potentially represents a ‘disruption of a *different* kind’ for young people living in these circumstances. Our study therefore extends previous research on family practices in changing and challenging circumstances and suggests that there may be situations in which the moral obligation to care for children and young people can be overridden without sustaining the loss of a moral reputation, at least for adults in the family. The imperative for family members to provide care for the dying in the home space inevitably influences the extent to which young people can depend on parents or other family members for the support they may have received in the past. The drive towards delivering end of life care in the home in order to facilitate a good death may therefore be incompatible at times with promoting the best interests of children and young people.

Nevertheless, Ribbens McCarthy, Hooper and Gillies (2013) have argued, ‘it is important to avoid using children’s best interests in a way that assumes it is simple to know what they are, and that even when we agree what they are, that they necessarily trump all other considerations’(2013, 16).This exploratory study of young people’s experiences of family life when they have a parent who is at the end of life raises the question of what moral tales of family we *should* tell in response to the competing imperatives for families to care for children and to care for the dying. Young people’s accounts of living with dying point more broadly towards the need to build a narrative of *a good dying* to counterbalance the discourse of a good death. The construction of such a narrative requires less emphasis on idealised notions of the very end of life for the individual, and more on the spatial, temporal and relational dimensions of dying in the home space, and on enhancing the everyday experiences of all family members over the trajectory of a life-limiting illness.

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