Caring to the End:

Exploring the family lives of young people with a parent at the end of life

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ABSTRACT

This thesis reports on an in-depth, qualitative study of the family lives of young people with a parent at the end of life. Family is an important concept in end of life care; the support and comfort of family members is thought to be valued by people at the end of life, and the presence of family is widely understood as essential to a 'good death'. However, attempts to interrogate what is meant by 'family' in these circumstances have been limited. Research studies in psycho-oncology and health sciences have tended to substitute one adult as a proxy for family. Consequently, little is known about young people's experiences of living with dying.

This study employed a multiple perspectives methodology to privilege the views of young people whilst taking into account the familial and wider social context in which young people live. The study is based on semi-structured interviews with ten young people (aged 13-21) with a parent in the last year of life. In addition, five family members were interviewed, each of whom was nominated by a young person. Young people's accounts were analysed using the voice-centred relational method, 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 an analysis of how young people understand and experience the relational constructs of family and care.

The results and discussion of the study findings are presented according to the three major subject areas of family, care and resources. The meaning, practice and moral significance of family and of care in the everyday lives of young people are examined in the light of wider social discourses on young people's involvement in care and on 'doing family', particularly in the context of end of life care.

Young people in the study talked about family in terms of presence, closeness and care; meanings that conflicted with their everyday experiences of absence, distance and loss. The acknowledgement that

some family members were unwilling or unable to *be there* was troubling for young people and disrupted their sense of belonging to a proper family.

In particular, the limited ability of parents to be there as a consequence of parental illness challenged the moral imperative for family to put the needs of children first. Instead, the need to provide care for a parent presented families with a new moral imperative to care for the dying. Young people wanted to be there for their parent; providing care was thus one response to *getting on with* everyday life. Furthermore, in caring for others, young people also cared for themselves by ensuring that their parent remained with them for as long as possible.

Friends were named as the most important source of support for young people. Many young people had little contact with service providers, and those who had received support were sometimes ambivalent about its effectiveness. Most young people were able to articulate a future for themselves beyond the death of their parent, and this future narrative contributed a sense of meaning and purpose to their lives in the present.

This study adds to current understandings of living with a parent at the end of life by applying a sociological lens to draw attention to the interpersonal and wider social factors that impact on young people's experiences of living with dying. I conclude that, whilst living with dying is undoubtedly troubling at times, there is also a mundanity seldom acknowledged in the literature in that young people accommodated their experiences in and through the everyday routines and practices of family life. Research, policy and practice in end of life care may benefit from more emphasis on the relational and often lengthy experience of living with dying, and on factors that may help to promote *a good dying* for all family members, including young people.

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CHAPTER ONE: INTRODUCTION

This thesis reports on a research study which aimed to address the gap in current understanding of young people's family lives when they have a parent at the end of life. To date, young people's experiences of living with a parent who is dying have received limited research attention, and therefore little is known about young people's perspectives on family life when a parent is in receipt of end of life care. In particular, the complex and nuanced understandings of 'family' and of the practice of care within families, both of which have been developed within the field of sociology, are missing from much of the literature on family care at the end of life, although there has been a growing interest in research in this area (Almack et al., 2010; Broom and Cavenagh, 2010; Broom and Kirby, 2013). The current study adds to the literature on family care at the end of life by examining the accounts of young people themselves. Young people were interviewed about their experiences of living with a parent at the end of life, the routines and practices that constitute everyday family life when a parent is dying, and the effects of parental illness on young people's own lives, both now and in the future.

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). The presence of family also matters to practitioners and policy makers in end of life care. The support provided by family and friends is increasingly regarded as an integral part of health and social care provision in the UK. Research produced by Carers UK in 2015 calculated that the economic value of care provided by family carers is £132 billion per year; close to the total annual cost of health spending[1]. It is estimated that 500,000 people are providing informal care to people

[1] Available from http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015

approaching the end of life (Payne and Hudson, 2008); a figure that is likely to increase in line with the demographic shift towards an aging population supported by a policy framework aimed at increasing the number of deaths that take place at home (Department of Health, 2008).

The importance of family care to end of life care provision is reflected by a growing body of research examining the roles, responsibilities and experiences of family members in delivering care to people approaching the end of life. Researchers have considered the process of becoming a carer (Smith, 2009), the support needs of carers (Costa-Requena et al., 2012), the efficacy of interventions to support carers (Harding et al., 2011) and future research priorities in this area (Hudson and Payne, 2011). However, as I will go on to discuss, 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 family 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. However, it is estimated that 5% of young people will have experienced the death of a parent by the age of 16 (Parsons, 2011), and that 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 UK, and merits further investigation.

This research study was the result of a funded scholarship developed in collaboration between a School of Health Sciences and a School of Sociology and Social Policy, and therefore from the outset, it was intended as an inter-disciplinary investigation. The study offered an opportunity to approach the subject of young people and parental life-limiting illness from varied angles and to apply different lenses to the formulation of a research enquiry. An early starting point was the potential for drawing on an established body of research on the experiences of young carers who have a family member with a disability or a long term condition to explore family care at the end of life. This approach suggested potential research questions about what type of caring activities young people undertake when they have a parent at the end of life, for how long, and the consequences for young people's health, educational attainment and social opportunities.

Whilst these are important considerations, I began to question whether they risked 'flattening' the experiences of young people to fit the concerns of an adult agenda based on the framing of young people involved in caring for a family member as 'at risk' (Frank and McLarnon, 2008). Here, I drew on my own experiences of caring for a family member at the end of life, both as a young person and as an adult, to arrive at the decision that I wanted to carry out a more open-ended exploration of young people's experiences, and to offer young people living with a parent at the end of life the opportunity to talk about their everyday lives without the presumption that these lives are being lived under the threat of damage.

I reflected that, in caring for family members at the end of life, I had never considered myself to be a 'carer'; a factor that is often identified in research on family care (Harrop et al., 2014; Molyneaux et al., 2011; Smith, 2009). Providing care had simply been a part of what families do; an expression of the mutual commitment and reciprocity that are ideally understood to characterise relationships between close family members (Finch and Mason, 1993; Ribbens McCarthy, 2012). I could also bring to mind plenty of occasions on which I had felt cared for, therefore the

simple binary between carers and those who are cared for in health and social care research and policy appeared to obfuscate the multiple and complex dynamics of care between family members in everyday lived experience.

Furthermore, I was aware that although providing care to someone at the end of life can be extremely difficult at times, it is a universal human experience to face difficulties and challenges in life, and the extent to which one event may be experienced as more troubling than others may vary significantly according to individual circumstances (Ribbens McCarthy et al., 2013). It therefore appeared important to me to enable young people to give their own accounts of living with a parent at the end of life, and to try and understand these experiences in the context of young people's specific and localised familial and social lives.

In the following chapters, I present my account of the study that emerged from these reflections and from my experience of conducting inter-disciplinary research to investigate the involvement of young people in end of life care. This in-depth qualitative study of the family lives of young people with a parent at the end of life explores how the on-going experience of parental illness is incorporated into young people's everyday lives and seeks to stay close to the perspectives and the language of young people themselves.

Chapter Two expands on this introduction by providing a review of the relevant research literature and drawing attention to the limitations of current research for an understanding of young people's experiences of living with a parent at the end of life. I begin by discussing the literature on family care at the end of life. This brings the current study into focus, in that it is the specific circumstances of living with a parent in need of end of life care that forms the context of young people's everyday lives. I consider the conceptual framework that underpins the iteration of family care through end of life care policy, adult perspectives on providing care for a family member, and research on interventions to support family

carers. I then introduce the smaller body of research on young people with a parent at the end of life, which tends to be framed in terms of factors that contribute to risk, resilience and coping in young people. I summarise social policy research on young carers to consider the potential for this theoretical perspective on family care to shed light on the everyday lives of young people with a parent at the end of life. Finally, I introduce sociological research on young people who are living in difficult circumstances and identify a potential framework for exploring the experiences of young people in the current study.

The study set out to expand on current understandings of family care at the end of life by drawing on more complex and nuanced interpretations of the meanings of 'family' and 'care'[2] primarily elaborated by sociologists. Therefore, in the later part of Chapter Two, I review the theoretical literature that has informed my understanding of the concepts of family and care. I conclude the literature review by summarising key propositions derived from the literature that underpin my interpretations of family and care in young people's accounts of their everyday lives.

Chapter Three presents the methodology for the study and provides a rationale for adopting a multiple perspectives approach to this exploration of the family lives of young people with a parent at the end of life. Decisions taken with regard to participant recruitment, methods of data collection and analysis are explicated, and ethical issues pertaining to the study are discussed. I also reflect on the process of carrying out the research and draw attention to issues raised by the study in relation to gaining access to young people, the recruitment of family members and the dynamics of the research interviews.

Chapters Four, Five and Six present and discuss the research findings under the main thematic headings of Family, Care and Resources. In each of these chapters, extracts from the research interviews are provided

[2] I introduce the concepts of 'family' and 'care' in quotation marks here to indicate that these are contested terms, as I go on to explore. However, hereafter I omit the quotation marks to facilitate reading of the text.

alongside my interpretations of the study data in order to illustrate the iterative process of generating research outcomes in this exploratory study. Chapter Four begins by considering the meanings, practice and moral tales of family in young people's accounts of living with a parent at the end of life. I explore the language young people use to talk about family, the 'normality' of living with dying for young people, and the practices that support young people in getting on with their lives. I discuss communication between family members as a specific set of practices pertinent to end of life care policy and practice. Finally, I reflect on the dissonance and discomfort experienced by young people when the moral imperative of family life is breached in response to the approaching death of a parent.

Chapter Five follows a similar pattern in presenting the meanings, practice and moral tales of care in young people's accounts. Again, I begin by examining the language young people use to talk about care as a means of exploring the presence of care in young people's everyday lives. I elaborate on the practice of communication between family members introduced in the previous chapter by describing how young people communicate *with care*. I then consider how young people and family members organise the doing of care by exploring the practice of negotiation and the notion of obligation in young people's accounts. I examine whether and how young people identify with the term 'carer', examples of when care is a source of conflict between family members and ways in which young people balance the need to care for others with care of the self.

In Chapter Six, I turn to the resources young people draw upon to ameliorate the effects of living with a parent at the end of life. I consider the importance of friends and family-like relationships to young people in the study, young people's experiences of statutory and voluntary sector services, and the potential for young people's future lives to act as a resource, even though thinking about the future entails an acknowledgement that their parent will no longer be with them.

Chapter Seven draws together the discussions in the previous chapters to provide a summary account of the family lives of young people with a parent at the end of life and to highlight what this study adds to understandings of young people and family care in the context of end of life care. In particular, I suggest that whilst living with dying is undoubtedly challenging at times, there is often a mundaneness to family life when a parent is dying that is seldom acknowledged in the literature. Young people may be living with dying for many years and find ways to accommodate their experiences of parental illness in and through the everyday routines and practices of family life. As parental health deteriorates, the moral imperative for families to put the needs of children first is undermined by a new imperative for family members to care for the dying. The implicit recognition of this change in priorities disturbs the meaning and experience of family for young people. The practice of caring for others is one response to changing and challenging circumstances, through which young people are also able to care for themselves. Many young people retain a sense of their own future lives beyond the death of their parent, and this can enhance the capacity to keep going in the present.

Finally in Chapter Seven, I highlight some implications of the study findings for service providers who work with young people and with families when someone is at the end of life. The experiences of young people in the current study suggest that young people may have little or no opportunity to seek support from services when they have a parent who is dying. The sensitivities that surround discussions of dying and death in the UK appear to be amplified by the presence of young people, and more needs to be done to open up spaces for young people to reflect on their experiences of living with dying, should they wish to do so.

In this chapter, I have introduced the broad aims and scope of the current study, and I have outlined the structure of the thesis. Before moving on to the literature review, I provide a brief explanation of key terms used in the study; in particular, family care, young people, and end of life.

1.1. KEY TERMS IN THE STUDY

1.1.1. Family care

Research in end of life care often makes use of the term 'informal care' to describe unpaid care provided outside of the statutory and voluntary sector by carers who may be relatives, close friends or neighbours of the person in need of care. In practice, most research focuses on care provided by a spouse, partner or adult child.

Since the study focuses on care provided by young people in a family setting, the term 'family care' will be adopted in line with the National Institute for Health and Care Excellence (NICE) definition of family carers in end of life care as, 'lay people in a close, supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management' (NICE, 2004: 155). NICE apply a broad definition of family including, 'those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient' (NICE, 2004: 155).

1.1.2. Young people

The term 'young people' will be used as a shorter term than 'children and young people' to refer to a person up to the age of 18. It is recognised that a large sociological literature exists which defines 'children' and 'young people' as differently located within the life course; however, as Gallacher and Kehily (2013) summarise, 'They are sociocultural ideas rather than absolute facts, and come to have very different meanings in different places at different times' (2013: 214).

I therefore employ 'young people' as a general term in this study, but it will be defined more specifically in the methodology chapter (section 3.7.3.) in relation to the young people who were invited to take part in the current research.

1.1.3. End of life

This study is interested in the specific experience of living with a parent who may die in the relatively near future, as this potentially represents a significantly different circumstance to living with a parent who has a chronic, long-term physical or mental health condition, who may continue to require family care for many years.

Consequently, the term 'end of life' will be applied in line with the National Council for Palliative Care definition, 'people are 'approaching the end of life' when they are likely to die within the next 12 months'[3].

All of the young people in the study were living with a parent who had been identified by a practitioner as meeting this definition. However, some of the research studies referred to in the study apply different terminology; for example, 'life-limiting illness' or 'advanced parental illness'. I have also used these terms where it is not clear that the definition of end of life has been applied, or when a point may be relevant at other stages of the parent's illness trajectory, and not only in the last year of life.

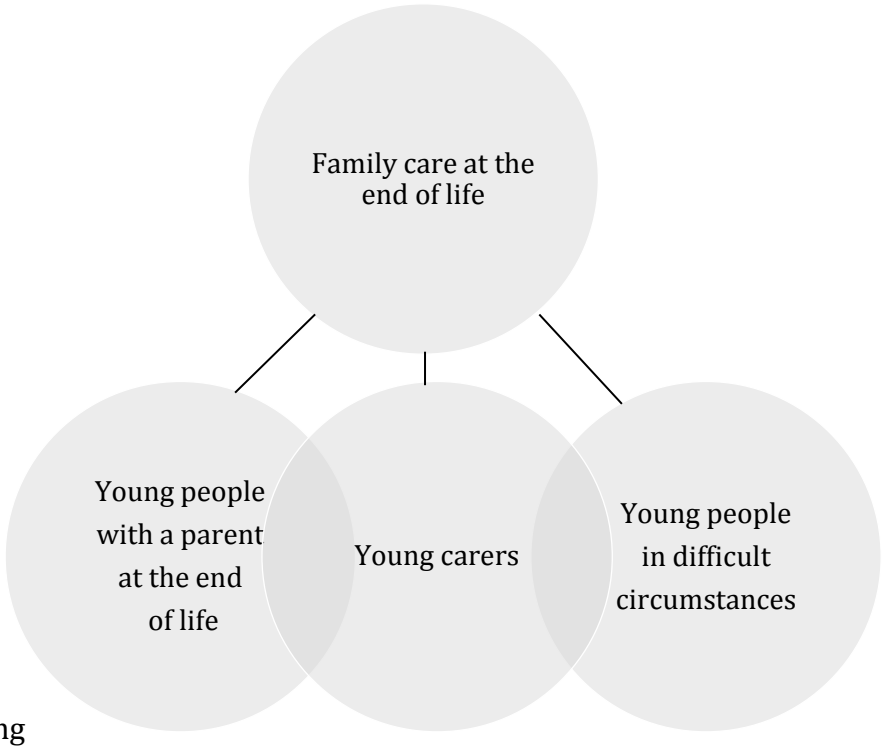
[3] Available from http://www.ncpc.org.uk/sites/default/files/Booklet.pdf

CHAPTER TWO: THE LITERATURE REVIEW

2.1. INTRODUCTION

There is currently a relatively small amount of research that specifically addresses young people's experiences of living with a parent at the end of life; therefore, in addition to reviewing the available literature, I have drawn on research from a number of areas that potentially shed light on young people's family lives when they have a parent at the end of life. The literatures I have incorporated in this review are illustrated in Figure 1. My aim in drawing together these diverse fields of research and in approaching the subject from different perspectives is to provide a rich description of the context in which the current study is located. I identify how the subject area of living with advanced parental illness is shaped by the disciplinary perspectives that have predominantly informed these fields and consider the implications for generating new knowledge through the current study.

FIGURE 1: DIAGRAM OF RESEARCH AREAS FOR THE LITERATURE REVIEW



I begin by considering

the research on family care and on the experiences of family members in providing care to someone at the end of life. I briefly explore how the iteration of family care in end of life care policy and practice has been underpinned by the discourse of a 'good death' before summarising the main research findings on family carers. As I have indicated, this research tends to focus on one adult who is identified as the main carer and whose experiences act as a proxy for family in the explication of family care at the end of life.

Research on young people living with a parent who is dying has 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). This literature is reviewed in the third section of the chapter. In general, studies of the experience of parental illness and of family care when someone is at the end of life have tended to be located in the fields of psycho-oncology or health sciences. A limitation of this research is that it mostly considers the young person or the family carer in isolation and pays little attention to relational aspects of everyday family life when someone is dying. I therefore consider research on the experiences of young people who provide care for a family member with a disability or a long-term condition to examine whether the social policy discourse of 'young carers' offers an alternative framework for understanding young people's experiences of living with a parent at the end of life.

The third section of the chapter concludes by reviewing some examples of sociological research which explores how young people respond to circumstances that disrupt everyday family lives (Backett-Milburn et al., 2008; Highet and Jamieson, 2007; Wilson et al., 2012). From a sociological perspective, young people's family lives are integral to an understanding of living in difficult circumstances; such that family may be regarded as a lens through which young people's experiences of living in difficult circumstances can be viewed, interpreted and understood. These studies also draw attention to the impact of wider social discourses on the

framing of individual and familial responses to changes that may be regarded as troubling (Ribbens McCarthy et al., 2013). I suggest that this approach may offer the potential to shed new light on the experience of living with a parent at the end of life by attending to the specific familial and social circumstances in which young people's everyday lives are lived.

In the final section of this chapter, I present a summary of key developments in sociological thinking with regard to the concepts of family and care and identify the theoretical constructs I have applied to generate an understanding of the experiences of young people in the current study.

Next, I begin by considering the relevance and limitations of the main findings from research on family care at the end of life. In commencing the literature review with research from the field of end of life care policy and practice, I draw attention to the absence of young people in current understandings of the family in family care, and establish the case for a closer scrutiny of young people's experiences of family when they are living in these exigent circumstances.

2.2. 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 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 been influential in determining how family relationships are viewed and understood when someone is at the end of life. In this section, I examine the discourse of a good death in order to explore how the concepts of family and care have become inexorably linked in the context of living with dying, and I consider the implications for understanding young people's experiences of living with a parent at the end of life.

A closer scrutiny of the research indicates that preference with regard to place of death may be 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 (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. The systematic review by Gomes et al. (2013) found evidence that around one fifth of patients change their mind with regard to preferred place of death as illness progresses. The overall picture with regard to preferred place of death is therefore ambiguous and often contradictory. 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.

The construction of a good death as one that takes place at home 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 if they have not been available to support a home death. The presence of family and close friends is an essential component of a good death; popular depictions of unaccompanied deaths at home are more often characterised as 'bad', and as indicative of troubling changes in the nature of family and wider social relationships (Caswell and O'Connor, 2015; Seale, 2004).

The conflation of accompanied dying at home with a good death appears to have deep historical roots, and may reflect a time before medical intervention in all aspects of life became the norm (Donnelly and Battley, 2010). Having no access to acute hospitals, previous generations had no option but to care for family members at home, and with little to offer in the way of pain relief, sitting with their dying relative and offering

comfort was seen as the highest form of service they could perform (Humphreys, 2001). The tenacity of an accompanied death at home as the contemporary ideal of dying in the twenty-first century indicates the continuing importance of family presence to the provision of 'good' end of life care, but also underscores the high moral stakes for family members who are unwilling or unable to offer support.

Nevertheless, it is possible that the current drive towards home based care at the end of life may be less concerned with facilitating a good death experience and more motivated by economic pressures. Research conducted on behalf of Marie Curie (Chitnis et al., 2012) estimated that the cost of providing one day's community care at the end of life is £145 compared with £425 for one day in a specialist palliative in-patient bed. In this context, promoting an approach to policy and practice aimed at enabling family members to provide care at home may be regarded as a sound financial investment, particularly when governments are seeking to reduce expenditure on public services (Williams, 2012).

The wider discourses that inform 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. Whilst individuals often take into account the presence of family members in making decisions about end of life care (Gomes and Higginson, 2006), this process is far from unambiguous or straightforward. For some, the reassurance that family 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).

A major limitation of this research in relation to the current study is that it does not take into account the presence of dependent children as a factor in making decisions with regard to end of life care. Studies reviewed have

generally involved older people, or at least the assumption that the respondent will be old when considering a hypothetical preference for a place of death. One qualitative study in which 36 practitioners were interviewed about their experience of end of life care discussions with terminally ill patients quoted a father who stated that he did not want his children to see him in the final stages of dying (Munday et al., 2009). Conversely, a study from the USA involving nine parents with advanced cancer and ten of their children found that optimising the limited time they had left together was of great importance to families with a parent at the end of life (Sheehan and Drauker, 2011). It is therefore possible to identify factors that may influence decision-making in families when a parent is dying, but more research is needed to elaborate the relationship between preferred place of death and the presence of children.

Addressing this gap in the literature would help to illuminate the process by which young people become involved in family care when a parent is at the end of life. So far, I have suggested that the policy discourse of end of life care, with its emphasis on promoting dying at home, is predicated on an enduring ideal of a good death which confers an obligation on family members to care for the dying. In the following sections, I further explore the literature on family care at the end of life, beginning with an examination of how the identity and role of 'family carer' is assumed when a family member has a life-limiting illness.

2.2.1. Becoming a carer

Whilst I have argued that end of life care policy sets up an assumption that family members will act as care providers for a person in need of end of life care, the process by which the identity and role of family carer is adopted remains to be addressed.

The National Institute for Health and Clinical Excellence (2004) describes a 'family carer' as follows:

> 'A broad definition of 'family' is used, including those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient. Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management' (2004: 155).

A review of the literature indicates that the process of identifying who is a family carer tends to be poorly defined or absent in many research studies. Where an explanation is provided, family carers may be self-identified or identified by a medical practitioner or a patient as a provider of care (Bee et al., 2009; Funk et al., 2010). In general, the identity of 'main carer' tends to be assigned to one person in a family, usually the spouse or an adult child of the person who is at the end of life, sometimes with the acknowledgement that other family members and close friends may offer additional support (Thomas et al., 2002).

These findings may reflect the fact that a large proportion of research on family care at the end of life examines the experiences of older people living alone or in dyadic, spousal relationships. Alternatively, the tendency for research studies to identify a main carer may duplicate a practice that is often adopted by practitioners in end of life care, and can be useful in that it simplifies the process of working with the family to facilitate family care (Hudson et al., 2012). For practitioners, the aim is often to establish a point of communication with family members in relation to meeting the needs of the ill person. The prevailing approach of identifying a main carer therefore reflects the policy and practice driven nature of research on family care at the end of life, where the intention has been to guide health practitioners in optimising the experience of patients and minimising the 'burden' on family carers (Thomas and Morris, 2002). In practice, a population survey carried out in South Australia reported that 56% of those who self-reported providing care to someone at the end of life were extended family members or friends,

indicating that family care at the end of life is likely to be more diverse than the model of a main carer implies (Burns et al., 2013).

Some qualitative studies have explored the 'journey' family members undertake in becoming a carer for someone at the end of life (Seal et al., 2015; Smith, 2009). In these studies, the process of adopting the identity of a carer begins early in the illness trajectory; for example, at the point of diagnosis. The motivation to provide care is often linked to the respondent's existing relationship with the ill person; one man interviewed in Smith's study stated:

> 'Cos when you're actually married to someone you're there through thick and thin anyway aren't you? If I was ill she'd look after me, and if she was ill I'd look after her.' (2009: 70)

This quote demonstrates the relational significance of care provided by family members at the end of life, whereby caring activities are interpreted as an extension of existing emotional commitments and are based on notions of reciprocity, mutual obligation and love (Linderholm and Friedrichsen, 2010). This iteration of family care contrasts with the notion of care as a burden more often found in the psycho-oncological research (De Korte-Verhoef et al., 2014; Whittingham et al., 2013). The editorial of a recent special edition of a journal introduced the subject of the family carer stating, 'It is a challenging and demanding role, which few people aspire to, but which many will have thrust upon them, in often difficult circumstances and following a 'crisis'' (Payne and Grande, 2013: 579). Whilst the challenges of providing family care at the end of life should not be overlooked and will be addressed later in this chapter, the meaning of care as an everyday expression of a significant and valued relational identity has received less attention in the research literature on end of life care and warrants further investigation.

In general, the motivation to care at the end of life and the process of accepting the responsibility to care by individuals within families has not been widely explored in end of life care research. This process is likely to

be more complex in families that include young people (Coyne et al., 2012; Forbat et al., 2009). The provision of care by a young person for a parent is not considered to be a normative experience for young people in the UK (Becker, 2007). Furthermore, the relational identities of 'child' and 'parent' incorporate particular cultural assumptions with regard to individual agency and moral responsibility that influence how the actions of family members are presented and interpreted (Ribbens McCarthy et al., 2000). For example, Smith and Skilbeck (2008) raise the issue of choice and suggest that interventions to support family carers 'should assist the carer to take up or not take up the caring role' (2008: 330). The extent to which a family member, and in particular a young person, can choose not to care and the implications of this choice for the individual, the person at the end of life, other family members and service providers needs to be better understood. A sociologically driven model of care that enables an interrogation of caring practices and the meanings attached to care within the context of family may help to support this.

Finally, it has been noted that many family carers do not recognise the term 'carer' or apply it to their own circumstances (Harding and Higginson, 2001; Harrop et al., 2014). As demonstrated in the previous quote from Smith's (2009) research, caring for a family member is often regarded as a facet of an existing relationship, rather than 'carer' being a distinct role associated with the adoption of a new identity. Broom and Kirby (2013) suggest that the lack of a theoretical model of family in end of life care may be counter-productive in that it leads to a tendency to obfuscate the roles, inter-relationships and decision-making processes that both shape and deliver family care at the end of life. Sociological research on care highlights the interdependencies in relationships of care in everyday life (Barnes, 2012; Rogers and Weller, 2012), and suggests that the dyadic model of 'carer' and 'cared for' is rarely adequate to describe the complexities of caring in the context of the family.

Having considered the literature on becoming involved in family care, I turn now to the delivery of care and examine the research on what family carers do in the process of caring for someone who is at the end of life.

2.2.2. The practice of caring

In the previous section, I suggested that the practice of caring for a family member at the end of life is often regarded as an extension of an existing role and relationship. However, the implications of living with a life-limiting illness are likely to result in changes to the everyday routines and activities that family members undertake within existing relationships (Thomas et al., 2002). Research studies have focussed on these changes as a manifestation of what is involved in the practice of family care, and as a means of assessing the impact of providing family care at the end of life (Thomas and Morris, 2002).

The nature and extent of caring activities undertaken by family members is likely to vary throughout the illness trajectory since for many people, the experience of a life-limiting illness may involve periods of remission, recurrence, active treatment and palliative care (Smith and Skilbeck, 2008). The practice of caring may begin with seeking information on behalf of the ill person at the point of diagnosis (Forbat et al., 2009). As illness progresses, family care may involve taking more responsibility for household tasks and the provision of personal care (Thomas et al., 2002). Towards the end of life, family carers may assist with symptom management, pain relief and the provision of nursing care (Armes and Addington-Hall, 2003; Bee et al., 2009). The practice of care is therefore not static, but is subject to continuous monitoring and revision, requiring significant adaptability on the part of the family carer (Clemmer et al., 2008).

Clemmer et al. (2008) carried out a qualitative secondary analysis of an ethnographic study of family roles in the provision of end of life care. The researchers describe how in responding to the needs of others, family carers re-prioritise existing responsibilities in an attempt to balance their

multiple roles and relational identities. The practice of providing care at the end of life therefore entails added labour for the family carer in terms of navigating commitments to a range of significant others in the uncertain and evolving context of living with a life-limiting illness. This period of change and uncertainty may continue for a long time; illness trajectories are difficult to predict and new treatments shift the parameters for prognosis in end of life care (Murray and Sheikh, 2008). Smith's (2009) qualitative study of 16 family caregivers illustrates the practical and emotional difficulties encountered by family carers when their involvement in care extended beyond the period originally anticipated. Smith describes the tension and ambivalence experienced in caring for a family member over an unexpectedly protracted timespan as unique to the situation of end of life care.

In addition to providing practical care and re-negotiating their responsibilities to family members and significant others, a major task for the family carer is the provision of emotional support (Thomas et al., 2002; Penrod et al., 2012). Family carers are described as 'maintaining a positive outlook for the ill person' (Smith, 2009: 71), striving to preserve the regular pattern of 'normal' life (Penrod et al., 2012: 180) and 'hoping against hope' (Williams et al., 2013: 7). In a narrative study of 23 female carers, Williams et al. (2013) elucidate this latter concept in terms of the tension between hoping for the continued existence of the person at the end of life and hoping for their peaceful demise. These qualitative studies demonstrate the particular complexities of emotional care for a family member who is at the end of life, and shed light on how family care at the end of life may differ from caring for a family member with a chronic condition or an acute illness (Williams et al., 2014).

The practice of caring at the end of life thus incorporates both a physical and an emotional dimension, with the extent to which a family member is engaged in caring activities being dependent on factors such as gender, age, the relationship with the ill person and the level of external support available (Smith and Skilbeck, 2008). Following a systematic review of

109 studies of family care at the end of life, McGuire et al. (2012) called for further research on the relative contribution of each of these factors in shaping practices of care between family members. All of the studies included in the review examined the experiences of adult carers; much less is known about young people's involvement in providing care for a family member at the end of life. The population survey by Burns et al. (2010) indicated that 14.4% of those who reported providing 'hands on' care for someone at the end of life were age 15-29, but there is no definition of what is meant by 'hands on' care, and no assessment of respondents' involvement in providing emotional support in this context. A small number of studies describe young people taking responsibility for helping other family members as a means of coping with parental illness. These studies will be reviewed later in this chapter (section 2.3.1.).

In this section I have summarised research on the practice of caring for a family member who is at the end of life. It is possible that a young person with a parent at the end of life may be involved in carrying out some or all of these caring activities, and therefore the nature and extent of young people's participation in care in the context of end of life care merits further examination.

In the following section, I consider research on the outcomes of caring for family members who are providing care to someone at the end of life.

2.2.3. Outcomes for carers

The impact of providing care has been the subject of a substantial body of psycho-oncological research involving the use of psychometric testing to assess a range of outcomes for carers and to identify potential risk factors (Grande et al., 2009). As a result, involvement in family care is now widely presented as incurring an increased risk of physical and psychological morbidity, financial disadvantage, social isolation and even increased mortality (Costa-Requena, 2012; Hudson and Payne, 2011; Schulz and Beach, 1999). This research has been associated with the construction of caring as a burden (Thomas and Morris, 2002), and others have warned

that this may result in, 'a danger of pathologising caregiving and inadvertently socialising caregivers to expect burden' (Hudson, 2004: 58).

Nevertheless, the physical and emotional labour involved in caring for someone at the end of life is likely to be experienced as challenging by some family carers. In a randomised control trial of an intervention to support family carers, Hudson et al. (2013) found that over 50% of the 275 carers who entered the trial met the threshold for psychological distress as measured by the General Health Questionnaire (GHQ). Hudson et al. suggest that failing to offer support to family carers in this context constitutes a breach of care, and call for more services to assist carers. This perspective, with its focus on outcomes and interventions for carers, reflects the positioning of family care at the end of life within a framework of evidence-based practice as advocated by health and social care policy. An important driver for research on family care at the end of life has been to identify carers who may benefit most from receiving support, given the constraints on available resources (Hudson, 2013). This wider context may have led to the privileging of research on 'measurable' aspects of the carer experience at the expense of developing a more nuanced understanding of the everyday experience of living with dying. For example, it is not always discernible whether the adverse outcomes reported by psychometric studies are a consequence of the practice of care, or of proximity to death.

A mixed methods study by De Korte-Verhoef et al. (2014) used a scaled questionnaire to assess the degree and type of burden experienced by 74 family carers and found that the proportion experiencing a fairly heavy or severe burden increased from 32% three months before death to 66% one week before death. During the week before death, 95% of carers described the burden as emotional compared with 29% who reported a physical burden. These results appear to indicate increased levels of distress in carers as a family member approaches death, but it is less evident whether distress in this context is related to the practice of care or to the anticipation of imminent loss. Furthermore, the majority of

participants reported that they did not experience care as a burden. In qualitative interviews with 18 carers, many reported 'it was normal to care for and support their partner or parent because previously the loved one had cared a lot for them, and therefore the burden did not feel like a problem' (2014: 5). These qualitative findings point to the importance of the meaning of care as expressed by the family carer to an understanding of the experience of providing care at the end of life.

Other studies have identified positive outcomes for family carers involved in end of life care including strengthening relationships, gaining new skills and increasing self-efficacy (Hudson, 2004; Wong et al., 2009). In a discussion paper on family care in the context of cancer, Thomas and Morris (2002) call for an increase in qualitative research from a sociological perspective to, 'bring to light the multi-layered experience of managing the patient's cancer and its social consequences' (2002: 181), and to act as a counterbalance to the psycho-oncological focus on intrapersonal consequences for the individual.

Thomas and Morris (2002) suggest that the development of psycho-oncology as a specialist field was particularly influential in constructing family carers as co-users of services, whilst more sociological approaches remind us that, 'carers and patients are not passive victims in their cancer dramas, but are purposive social actors engaged in the shaping of their cancer experiences within specific social settings and socio-cultural circumstances' (2002: 181). Again, a better understanding of the meanings carers attach to caring practices and to the contexts in which care takes place may help to illuminate the complexities of care in everyday lives, which may have been obscured by the dominant construction of family care as a burden.

In the final part of this review of the research on family care at the end of life, I examine studies on the effectiveness of services to support family members when they are caring for someone who is dying.

2.2.4. Interventions to support carers

Some researchers have set out to review studies of the efficacy of interventions aimed at providing support to carers in end of life care (Harding et al., 2011; Hudson et al., 2010). In general, reviewers have reported that research in this area is not theoretically or methodologically robust enough to allow for any conclusions regarding the suitability of one type of intervention over another to be reached (Hudson and Payne, 2011; Stajduhar et al., 2010), although there are suggestions that the overall quality of research is improving (Harding et al., 2011).

A number of difficulties with conducting evaluation studies in the context of end of life care are identified. Harding et al. (2011) refer to the relatively brief window of opportunity available for carers to establish new ways of coping and to demonstrate improved outcomes prior to bereavement. Molyneaux et al. (2011) suggest that lack of identification with the term 'carer' impacts on the take up of services, which may introduce bias into studies aimed at assessing the effectiveness of support for carers. Others have focussed on the variability in tools and methods used to gather pre and post intervention data, and questioned the reliability and validity of existing measures (Hudson et al., 2010).

Hudson and Payne (2011) are amongst reviewers calling for a major investment in the comprehensive evaluation of carer support through the application of the Medical Research Council's framework for evaluating complex interventions (Craig et al., 2008). This is regarded as necessary to establish an evidence base that is robust enough to inform the development of practice in end of life care. However, more recent studies involving the use of randomised control trials have encountered problems with participant recruitment and retention; Hudson et al. (2013) acknowledge that this was to be anticipated due to the likelihood of family members dying during the course of the study.

The adoption of a medical model in which support to carers is regarded as a health intervention may increase the tendency for end of life care

researchers to approach family carers as patients in need of treatment. Hudson and Payne (2011) refer to the need for, 'more insight into the effective 'dose' of support interventions' (2011: 866), and suggest that family carers' needs are, 'equal to and/or greater than the needs of patients' (2011: 865). However, it is not clear from the research that family carers themselves think about their experiences of care in these terms. Other studies report considerable ambivalence on the part of family carers to acknowledging their own needs, possibly due to a concern that in doing so, they may divert resources away from the person at the end of life (Harding and Higginson, 2001).

Instead of pathologising care, some researchers working from a sociological perspective have sought to interrogate care as part of everyday family life, and as an expression of our essential interdependence and moral relationality (Barnes, 2012; Rogers and Weller, 2012). Some studies have applied an understanding of care as a relational practice to explore the experience of family care at the end of life (Broom and Kirkby, 2013; Kirkby et al., 2014; Ward-Griffin et al., 2012). For example, an ethnographic study by Ward-Griffin et al. (2012) examines the impact of advanced cancer on the relationships between older adults receiving care, their families and professional caregivers with a view to elucidating relational factors that support optimal end of life care. There is potential to further develop the application of this theoretical framework in order to explore its relevance to understanding the experiences of young people with a parent at the end of life. This may help to increase awareness of the processes and practices involved in delivering family care, and inform a different approach to conceptualising and assessing the needs of family members when someone is in receipt of end of life care.

Having summarised some of the key themes in the literature on family care in the context of end of life care, I will now consider research on young people living in a family with a parent who is approaching the end of life.

2.3. YOUNG PEOPLE AND PARENTAL ILLNESS: COPING, CARING AND 'GETTING BY'

Research accounts of young people in families with a parent at the end of life tend to reflect a dominant discourse of family whereby children and young people are seen as being in need of care and protection and parents have a moral obligation to provide care (Elmberger et al., 2005; Stiffler et al., 2008). Sociologists such as Gillies (2011) have described how family is a political, as well as a cultural and historical construct, and have delineated how successive governments have sought to intervene in and regulate family lives. A contemporary iteration of the process of regulation is the concept of 'troubled' families and the increasing surveillance of families who may be experiencing troubles, or are identified as troublesome to others (Ribbens McCarthy et al., 2013).

The process by which events and experiences are deemed to be troubling and the consequences for those who are assumed to be troubled by their encounters with the vicissitudes and challenges of everyday life are themes that can be traced through the literature on young people and families with a parent at the end of life. End of life care research tends to constitute the young person as vulnerable, and in need of support in 'coping' with everyday family life in these circumstances (Kennedy and Lloyd-Williams, 2009; Thastum et al., 2008). The trajectory of parental illness is sometimes constructed as a period of 'pre-bereavement' (Chowns, 2010; Fearnley, 2015); a construction that assumes young people's everyday family lives are primarily shaped by their endeavours to manage the anticipated death of a parent.

The large body of research on the risks and outcomes associated with parental bereavement and on bereavement support for young people will not be scrutinised here. This study seeks to make a distinct contribution to the literature on young people and parental illness by focussing on living with dying, not living with death. As such, it is a prospective study of young people's everyday family lives while they are living with a parent

at the end of life in contrast to other research in this field, which has often involved retrospective accounts from young people whose parent has already died (Fearnley, 2010; Macpherson and Emeleus, 2007). The trajectory of many life-limiting illnesses suggests that young people may be living with dying for many years before they encounter death. My interest is in exploring how young people navigate the changes associated with their everyday experience of parental illness, rather than examining how young people deal with the event of a loss. Whilst I do not assume that one experience is more or less troubling than the other, it is possible that they may be differently troubling, and therefore young people's experiences of living with a parent at the end of life are worth further investigation.

The tendency to pathologise the experience of living with parental illness as an inevitable precursor to physical and psychological harm has already been noted in the literature on family care. The dominant paradigm of psycho-oncology tends to regard young people as passive victims of their experience and in need of protection and intervention, rather than as active agents responding to and interpreting change in and through their everyday family lives. As I go on to discuss, the unit of interest in psycho-oncological research is often the individual young person, and the focus is on psychometric testing to measure harm or to identify intrapersonal factors that contribute to resilience.

An alternative approach to conceptualising the experiences of young people with a parent at the end of life may be found in a small number of studies that consider young people and life-limiting parental illness from the perspective of a social policy discourse on young carers. Research on young carers has largely been underpinned by a theoretical construction of young carers as embodying a right to protection from harm. I will briefly review the literature on young carers in relation to end of life care, and will consider the utility of a children's rights approach to exploring the experiences of young people in the current study.

Finally, I will outline research from a sociological perspective that promotes a more relational approach to understanding the experiences of young people who are dealing with potentially troubling changes in their everyday family lives. For example, Wilson and colleagues (Wilson et al., 2012; Backett-Milburn et al., 2008) explore how young people participate in and shape the 'doing of family' when they are living in the difficult circumstances engendered by parental substance misuse. Highet and Jamieson's (2007) Cool with Change study examines how young people experience change in their everyday family lives and assesses the implications for the development of support services. These studies may provide a more useful model for the study of young people, family life and the practice of care in the context of end of life care.

I begin this part of the review by considering the research on risks associated with living with parental illness and on the individual and familial traits that have been identified as potentially protective factors in dealing with the damage assumed to be inflicted on young people living in these circumstances.

2.3.1. Risk, resilience and coping in young people and families

A growing psycho-oncological literature has emerged in the past ten years that has examined the evidence of a relationship between living with a life-limiting parental illness and psychological distress in young people. Some of this research focusses on the early stages of parental illness or does not differentiate findings according to illness stage. For the purpose of this chapter, I will summarise the findings of recent systematic reviews that have addressed the impact of living with advanced parental illness (Ellis et al., 2016; Huizinga et al., 2011; Phillips, 2014), along with additional findings from recent studies where relevant. All of this research relates to living with a parent who has cancer; one limitation of research in this field is the lack of inclusion of parents with other life-limiting conditions.

One reported finding is that older adolescents (age 15-18) who are living with advanced parental illness experience more psychological distress when compared with a general population than younger adolescents (age 12-14) (Rainville et al., 2012). This finding is attributed to the likelihood of older adolescents taking on more responsibility for household chores, although this is not measured in the study. These additional demands are presumed to conflict with the developmental task the researchers associate with adolescence of becoming more independent from the family, and are therefore assumed to be a cause of stress. However, an earlier review by Osborn (2007) did not find any evidence of a difference in social participation between adolescents living with parental illness and their peers. Other studies have demonstrated similar (Lindqvist et al., 2007) or better (Kühne et al., 2012) levels of psychological functioning amongst young people living with advanced cancer. These results have been described by reference to the notion of post-traumatic growth, whereby factors associated with parental illness are thought to have a positive effect (Wong et al., 2009a). These factors include a greater appreciation of life and an increase in intimacy between family members.

A systematic review by Huizinga et al. (2011) applies Su and Ryan-Wenger's (2007) theoretical model of risk and resilience to examine factors that moderate or mediate young people's responses to living with parental cancer. Moderators are defined as pre-existing variables that influence the intensity of the stressor (parental illness) for young people; and include age, gender, the availability of support and factors associated with the ill parent. Adolescent daughters are reported as more likely to exhibit psychological distress than sons (McDonald et al., 2016). This has been attributed to the likelihood of girls taking on more responsibilities in the home due to the gendered nature of care-giving, although it is also acknowledged that girls and women are generally more likely to report psychological distress than boys and men. Huizinga et al. (2011) conclude that it is difficult to determine the impact of the ill parent's gender since most studies focus on the experience of living with a mother who has

cancer. This bias is attributed to demographic factors; female cancer patients being more likely to have dependent children living at home (Weaver et al., 2010).

Mediating factors in responding to parental illness according to Su and Ryan-Wenger's (2007) model are those that do not affect the intensity of the stressor, but influence the young person's response. These include the young person's appraisal of their parent's illness, the coping strategies young people employ, and communication between family members. Whilst the systematic reviews include some quantitative studies that have looked for measurable effects across these domains, there are more examples of the use of qualitative research to explore these factors. I will return to consider the key findings from qualitative studies of young people's coping following a brief analysis of the limitations of psychometric research on risk and resilience in young people living with parental illness.

Huizinga et al. (2011) acknowledge that the studies included in their review are highly heterogeneous with regard to design, methodology, sampling and the psychometric measures used to assess effects, so it is difficult to compare or integrate findings from this research. The majority of studies are cross sectional, which limits the potential for causal inferences, sample sizes are often small, and the psychometric instruments used are generally designed to measure the effects of stress in the general population, and may not be suitable to assess the specific pressures associated with parental life-limiting illness. Nevertheless, and in spite of the inconsistent results recorded, Huzinga et al. (2011) report that young people's experiences of parental cancer may have 'long-term negative consequences' (2011: 239). This suggests that there may be a bias towards predicting negative outcomes from parental illness, even though it is difficult to establish that such outcomes exist.

Some research from a psycho-oncological or a family systems perspective sets out to examine the experience of living with advanced parental illness

by seeking the views of young people themselves (Huang et al., 2014; Kennedy and Lloyd-Williams, 2009; Philips and Lewis, 2015). This research is exploratory and qualitative in design and method, and focuses on the impact on young people and on strategies for coping with the challenges imposed by living with a parent at the end of life.

One systematic review and meta-synthesis of 16 qualitative studies suggests that young people experience a range of emotional responses to their parent's illness including shock, anxiety, anger, sadness and uncertainty (Huang et al., 2014). For some, the most difficult aspect of living with advanced parental illness is having no control over the disease (Philips and Lewis, 2015). Girls in particular expressed concerns about their own health and the possibility that cancer may be hereditary (Kennedy and Lloyd-Williams, 2009), although in Philips and Lewis's study of seven young people living with parental cancer, both boys (n=2) and girls (n=5) expressed this fear.

Parental cancer is described as intruding on young people's everyday lives and altering the roles and responsibilities of family members (Helseth and Ulfsæt, 2003). Young people reported changes including 'role reversals in which they became the caregiver for their ill parent' (Philips and Lewis, 2015: 852). In addition, young people described taking over household chores and looking after siblings in order to support their parent (Kennedy and Lloyd-Williams, 2009). These additional responsibilities impacted on the time young people spent pursuing other activities and interests. Kennedy and Lloyd-Williams (2009) interviewed eleven young people (aged 8-18) and found that for some, providing emotional support to their ill parent helped them to feel better, whilst others struggled to respond to their parent's emotional concerns.

A number of studies set out to identify the coping strategies adopted by young people (Helseth and Ulfsæt, 2003; Kennedy and Lloyd-Williams, 2009; Thastum et al., 2008). These studies draw on the work of Lazarus (1993) to describe coping in terms of the cognitive and behavioural

efforts young people employ to manage demands appraised as challenging or exceeding their personal resources. Coping is thus theorised as an individual, instrumental activity aimed at minimising the negative effects of an identifiable stressor. The most commonly reported coping strategies in relation to young people living with advanced parental illness were:

- Maintaining a sense of normality by continuing to adhere to everyday routines
- Seeking distraction through participating in activities or being with friends
- Talking about their experiences with parents, other family members or friends
- Taking responsibility for helping other family members

In a study of 15 young people aged 14-18, Maynard et al. (2013) found that searching for meaning or a deeper understanding of their experiences was a strategy adopted by some young people, who reported that they sometimes wanted time to themselves to process and make sense of what was happening in their lives. Young people also referred to spending time with peers who had lived in similar circumstances as a source of support, information, and a sense of hope that they would get through the experience of living with a parent at the end of life.

Helseth and Ulfsæt (2003) suggest that young people cope by 'going 'in and out' of the situation, both literally and emotionally' (2003: 355), and conclude that young people do not want to be disturbed by thoughts of their parent's illness all of the time. For some young people, attendance at school offered an opportunity to take time out from living with parental illness (Huang et al., 2014). Consequently, they preferred not to talk about their experiences with staff or friends at school and chose to maintain school as a place where they could be like any other young person, rather than a young person living with parental cancer.

In their study involving both young people and parents, Kennedy and Lloyd-Williams (2009) were interested in why children choose particular coping strategies. They found that the parent's preferred coping strategy influenced the young person's approach to coping. In particular, when parents adopted a more closed approach to communicating about parental illness and focussed on maintaining normality in everyday family life, the opportunities for young people to ask for support were reduced. Therefore, young people's strategies for coping were unintentionally limited by the actions of their parents. The relationship between communication, support and coping is seen to be particularly important for understanding young people's experiences of living with a parent at the end of life (Forrest et al., 2006; Thastum et al., 2008), and is worth further consideration.

Policy and practice in end of life care promotes the importance of open communication with and between family members when someone has a life-limiting illness (Department of Health, 2008). The ability to open up a conversation with someone who is dying or their family members, to listen effectively to their experiences and to provide appropriate information and support are regarded as vital skills for all of those working in end of life care (Duke and Bailey, 2008). In the context of the family, the ability of parents to foster a culture of open communication in relation to parental illness is seen as a significant contributory factor in determining young people's capacity for coping (Christ and Christ, 2006).

Empirical studies suggest that consistent, accurate and honest conversations from the point of diagnosis through to dying, death and bereavement may help to reduce anxiety and lead to better outcomes for young people (Beale et al., 2004; Chowns, 2009). However, research indicates that parents often shield young people from information when a parent is dying in order to protect them from distress (MacPherson, 2005; Turner et al., 2007). Nevertheless, a study by Forrest et al. (2006) of 37 mothers with breast cancer and 31 of their children (aged 6-18)

demonstrated that even young children may be aware that cancer can be life-threatening. Huang et al. (2014) conducted a systematic review followed by a qualitative meta-synthesis of 16 studies of young people's experiences of parental cancer. They suggest that young people's suppositions about parental illness may be 'worse than the reality' (2014: 502) if they are not kept informed about the diagnosis, treatment and prognosis; hence the emphasis on the importance of accurate information and knowledge of parental cancer in the studies reviewed.

Huang et al. (2014) found that parents and/or older siblings were the main source of information on parental illness for young people. However, many young people chose not to talk to their parents because they did not want to cause further distress, or they found it difficult to raise the subject themselves. Instead, young people are described as managing the impact of parental illness largely on their own (Helseth and Ulfsæt, 2003; Philips and Lewis, 2015). Helseth and Ulfsæt (2003) conclude, 'It is difficult to say whether this is an appropriate way for children to cope in difficult life situations, or whether more effort should be made to approach the children on this and make them open up' (2003: 360).

Some qualitative studies provide evidence of more positive outcomes of living with advanced parental illness. For example, some young people reported feeling closer to their family and wanted to spend more time together (Kennedy and Lloyd-Williams, 2009; Sheehan and Draucker, 2011). Kennedy and Lloyd-Williams (2009) suggest that further research is needed to find out if the positive aspects of everyday family life can be developed to assist young people in gaining a better overall experience of living with a parent at the end of life.

The review by Huang et al. (2014) concludes that, whilst it may have been hard to adapt to changes initially, many young people were able to adapt to living with parental cancer in time. They describe how 'cancer was gradually integrated into their normal life' (2014: 502) and became part

of young people's everyday experience. Similarly, in spite of the challenges they faced, young people in Helseth and Ulfsæt's (2003) study reported 'feeling good most of the time' (2003: 359), although this sense of well-being could be disrupted at particular points in their parent's illness trajectory, for example, during a hospital admission. Participants in Philips and Lewis's (2015) study also reported positive outcomes of living with parental illness; 'the parent's cancer helped shape them, influenced their self-image, fostered their own maturity, and enriched their own perspective on life' (2015: 856).

This review of the literature suggests that evidence from qualitative studies of living with a parent at the end of life may help to elaborate and enrich the contradictory data emerging from quantitative research. One indication is that there is no universal account of living with advanced parental illness, and that many factors may need to be taken into consideration in understanding young people's experiences of everyday family life in this context. One consequence of the dominance of an individualised, psycho-oncological approach in the current research is that the everyday relational context of family has tended to be neglected in favour of a focus on intrapersonal characteristics of young people and/or their parents.

The emphasis on coping as an intrapsychic cognitive or individual behavioural process overlooks the importance of relational factors in shaping young people's experiences of parental illness. Furthermore, the notion of coping is predicated on an understanding of young people's everyday lives as intrinsically threatened. An alternative perspective that takes into account the endurance and flexibility of the interpersonal relationships of care that underpin family life may shed further light on young people's experiences of, and responses to, living with a parent at the end of life. The argument for applying an alternative lens is supported by Philips and Lewis (2015) and Rainville et al. (2012), who comment on the paucity of a pathological model of maladjustment to describe how

young people contain the experience of parental illness in their everyday lives. These researchers call for more emphasis on change, rather than damage, in analysing young people's relationships with family members.

In the following section I consider research that draws attention to changes in relationships of care between family members by focussing on the experiences of young people as 'young carers'. I examine the potential of a perspective drawn from a social policy discourse on young carers for understanding the experiences of young people with a parent at the end of life.

2.3.2. Young carers and end of life care

Research on young carers has largely been driven by the development of social policy based on a theoretical construction of young carers as embodying the right to protection from harm. This section will briefly review the literature on young carers and consider the utility of a children's rights perspective to exploring the experience of young people with a parent at the end of life.

As I suggested in the review of literature on family care, the social construction of childhood as a protected space means that, whilst the majority of young people regularly participate in some household chores, young people in the UK are not expected to carry a heavy burden of domestic responsibility (Becker, 2007). However, research has demonstrated that some young people have significant caring responsibilities for family members. Figures from the 2011 Census suggest that 177,918 children aged 5-17 are caring for their parents, siblings or others[4]. This figure is likely to be a significant underestimation, since many young people and parents will not recognise the term 'young carer' or apply it to their own circumstances. Using a different

[4] Available from: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html

methodology, a BBC survey conducted in 2010 suggested that the actual number of young carers could be in excess of four times this amount[5].

Young carers are legally defined in the Carers (Recognition and Services) Act 1995[6] as, 'Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis'. Research on young carers suggests that the reasons why young people become carers include factors relating to family structure, such as the lack of available adults and the age and gender of young people (Aldridge and Becker, 1993); social and cultural expectations of the parent-child relationship (Evans and Becker, 2009); and wider structural factors, including poverty and the availability of health and social care services (Hounsell, 2013). Frank and McLarnon (2008) add, 'The majority, however, just grow into the role' (2008: 4), suggesting that in general, care practices within families evolve through unspoken processes of negotiation and implicit assumptions of interdependence between family members.

Young people's involvement in family care has been interpreted as placing them at risk of harm, particularly when they are very young, are caring for long hours or are involved with the intimate, personal care of an adult (Dearden and Becker, 2004). The notion of care-giving as conferring damage on young people is supported by survey data that points to the negative outcomes associated with being a young carer including health problems, emotional difficulties, underachievement in education, and limited social and leisure opportunities (Hounsell, 2013).

The duty to protect young carers is reflected in the Carers' Strategy (Department of Health, 2008a); the most recent version of a policy framework aimed at securing improvements in practice for all carers, including young carers. The End of Life Care Strategy (Department of Health, 2008) also recognises young people's involvement in family care

[5] Available from: http://www.bbc.co.uk/news/education-11757907
[6] Available from: http://legislation.data.gov.uk/ukpga/1995/12/contents/data.pdf

and states, 'The needs of child carers should be given particular consideration, so that they do not take on more than they can reasonably cope with' (2008: 107). However, there is no further guidance on how young carers should be identified, assessed or supported, and by whom. Freeman (1998) draws attention to, 'the real dangers of symbolic politics' in applying a children's rights perspective to understanding and interpreting young people's everyday experiences of care-giving, pointing out 'that rights without services are meaningless and that services without resources are impossible' (1998: 435).

Thus, although the policy discourse on young carers may have helped to illuminate a previously 'hidden' aspect of family care, particularly in relation to end of life care, there is little to suggest that it has changed the everyday experience of care in the majority of families with a parent at the end of life. Freeman's (1998) warning about the gap between policy and practice with regard to the children's rights discourse on young carers appears to be well founded in this context. Only a small number of research reports were identified that referred specifically to young carers in end of life care. The population survey by Burns et al. (2013) established that young people can be integral to the provision of end of life care, and indicated the need for more research into the experiences of young carers.

Allen (2010) and Baulkwill et al. (2012) both report on a young carers' group at St Christopher's Hospice in London. These articles, written in journals for practitioners working in end of life care, are intended to provide information on the process and benefits of establishing a support service for young carers, and offer little insight into the experience of care from the perspectives of the young people themselves. Gandy et al. (2012) describe a sub-project focussing on young carers, which was part of a wider study on patient and public involvement in end of life care. Interviews on the experience of end of life care services were carried out with three young people who had already been bereaved. The discussion makes use of a framework devised as part of a Barnardo's project on

young people caring for a parent with mental health issues, so it is not surprising that young people are reported as experiencing issues with service use that parallel those of young carers in other contexts. These include feeling invisible to service providers, who often did not talk to them directly, and not being involved in discussions and decisions with regard to their parent's care.

It appears that the policy recognition of the rights of young carers to receive support has so far failed to secure significant changes in practice with regard to provision for young carers. However, other researchers have raised a more fundamental concern with the rights based discourse of young carers, in that it marginalises and problematises parents who are in need of care (Clarke and O'Dell, 2013; Keith and Morris, 1995; Newman, 2002). Keith and Morris (1995) point out that the construction of a young carer as a welfare category is predicated on fixed assumptions concerning the roles of 'child' and 'adult', whereas these identities should be regarded as historically and culturally defined. Newman's (2002) analysis of the research on young carers identified issues with defining a young carer, such that some criteria used for definition could be applied to any young person living in a family where someone has an illness or a disability. Furthermore, Newman suggests that the negative outcomes associated with care-giving by young people may be attributable to poverty and social exclusion; factors often linked to parental illness, and may not be a product of the provision of care. Newman concludes:

> 'Young carers – like all children – dwell in a tangled web of reciprocal responsibilities, strong emotional ties and conflicting aspirations. In short, they live in families; social entities that are not easily deconstructed by the individualistic thrust of human rights discourse' (2002: 619)

A mixed methods study by O'Dell et al. (2010) examined young people's constructions of young carers and their parents and found strong assumptions amongst 46 young people aged 15–18 that family members

should care for each other. The researchers concluded that care-giving may be a more normative and expected aspect of young people's family lives than the young carers' discourse implies.

Barnes (2012) has also argued that the rights discourse employed to secure recognition for carers is polarising, and does not take into account the individual and shared biographies of care that characterise family relationships. She points out that most of us will be involved in multiple caring relationships throughout the life course and that there is therefore a justification for the interdependency of human existence to be better reflected in policy and practice intended to promote well-being. The ethic of care applied by Barnes suggests that family members negotiate the practice of care in and through their everyday lives, but that care cannot be considered as solely private, and is affected by the social and political environment in which care takes place.

My reading of the literature on young carers therefore suggests that further investigation of the processes and practices through which young people, parents and family members negotiate to secure care, protection and self-determination may help to develop a more nuanced understanding of young people's experiences of living with a parent at the end of life than that generated by the application of a children's rights discourse. In the following section of this literature review, I examine sociological research that has investigated how young people respond to changes and challenges in and through their everyday family lives. I consider whether viewing young people's experiences of living with a parent at the end of life through a sociological lens may add to existing knowledge and understanding of family care at the end of life.

2.3.3. Young people and family in difficult circumstances

Sociological research on the changes and challenges of everyday family lives brings into the frame two important sets of considerations. Firstly, researchers raise the question of whether such experiences should be understood as inevitable features of young people's family lives, or

whether some troubles should be regarded as avoidable, and therefore to be deflected away from young people. Related to this question are the issues of who decides which events are troubling, and what might constitute an appropriate response. Researchers such as Ribbens McCarthy et al. (2013) and Gillies (2011) have argued that government initiatives increasingly target families who are identified as the prime cause of societal problems, and in doing so, conflate the experience of multiple social and material disadvantages with anti-social behaviour through the application of a problematising discourse of 'troubled families'.

A second set of questions raised by sociological research relate to the framing of young people in research, policy and practice regarding young people's experiences of change. As I have discussed, the biomedical and developmental perspectives of young people as incomplete human beings (Prout and James, 1997) that tend to underpin research on young people's experiences of living with parental illness position young people as passive victims of the damage inflicted by their family circumstances. Similarly, the children's rights perspective of young people as vulnerable and in need of adult protection affixes young people and adults in a particular relational dynamic in which young people are placed at risk by their involvement in providing care. In contrast, sociological research brings into focus young people's agency and the impact of young people's decisions and actions on their everyday lives and on the lives of family members. Ribbens McCarthy (2007) has argued that the constraints imposed on young people's agency by their social positioning as 'youth' are as likely to lead to the negative outcomes associated with adverse events as the events themselves.

Research by Highet and Jamieson (2007) has highlighted how some changes may be experienced as both ordinary and troubling in the lives of young people. In their survey of 361 young people aged 10-14, 43% of young people said that someone close to them had died recently; for 4% of young people the death was of a parent. In addition, 36% of young

people said that someone close had been ill for a long time. It is therefore relatively ordinary for young people to have experienced serious illness and/or death in the family, and given the universality of dying, it is likely that death is an unavoidable presence in young people's lives. However, the experience of parental death is less common, and may lead to a loss of parental care or a reduction in a young person's access to other resources as well as the emotional experience of distress. Nevertheless Highet and Jamieson (2013) found that it was possible for some young people to talk about no longer being troubled by the death of a parent. They go on to explain:

> 'From the sociological perspective adopted here, what matters theoretically is the current state of play in terms of quality, extensiveness and resilience of sources of support for the self beyond the person or persons who are 'lost' that can continue to sustain a sense of self, help rebuild a damaged self or provide alternative narratives to the dominant discourse of troubling loss' (Jamieson and Highet, 2013: 138).

These factors are pertinent to research by Backett-Milburn et al. (2008) on young people living with parental substance misuse. Their interview study focused on the interactions, practices and processes that helped or hindered young people (aged 15-27) who were living with parental substance misuse. Backett-Milburn et al. use the term 'getting by' in preference to the more evaluative notion of coping in order to 'to encapsulate a more agentic notion of repertoires of everyday practices grounded in, but not constrained by, these particular childhoods' (2008, 464). Respondents described a range of disruptions, neglect, and violence among the difficulties they experienced and reflected an awareness that their family lives were not 'normal', but were differentiated by the stigma attached to parental substance misuse. Half of the sample described themselves as having been carers for their parent and/or siblings; care-giving was sometimes presented as a source of self-esteem and maturity, but sometimes made the transition to independence more difficult.

Backett-Milburn et al. (2008) point out that in childhoods permeated by disruption and change, young people experienced a complex pattern of shifting boundaries of care between their parent and themselves. The protective factors associated with getting by were rarely available to young people without associated costs. However, practices such as care-giving helped to engender a sense of agency and control and may have taken on an added significance for young people in navigating these challenging circumstances.

This research highlights the importance of relational practices of care to young people's experiences of living in difficult circumstances. Wilson et al. (2012) also draw attention to the moral significance of descriptions of care (or of the absence of care) in the family narratives of young people in the study. Young people were aware of the breach of a parental obligation to care for children that their accounts revealed, and struggled to present a narrative that would enable them to stake a claim on belonging to a 'proper' family. The discursive power of the idealised norm of family life and the emotional labour involved for young people in trying to repair and rebuild a coherent family narrative are potent themes in these accounts.

Sociological accounts of young people's responses to significant change in their everyday lives raise a number of issues relevant to the current study. Firstly, whilst the experience of life-limiting parental illness is invariably constructed as troubling in the existing research literature, more research is needed on how young people themselves experience their everyday family lives in this context. Studies that draw on the perspectives of young people may help to identify whether some changes associated with parental illness are experienced as more troubling than others, and when and how those who are concerned about the well-being of young people should respond (Ribbens McCarthy et al., 2013).

Secondly, applying a sociologically informed notion of 'getting by' to understanding the practices and processes that shape young people's

everyday lives may shed light on ways in which young people exercise agency in responding to parental illness and on the factors that enhance or diminish young people's agency in these circumstances. Ribbens McCarthy (2007) suggests that one way in which young people display agency is in searching for meaning through the construction of an autobiographical account. How young people make sense of their lives both now and in the future in their accounts of living with a parent at the end of life may inform an understanding of the significance of this deliberative, meaning-making process.

Thirdly, it appears that the interdependencies of care that underpin relationships between family members are particularly salient to an understanding of the experiences of young people when they are living in difficult circumstances. A more nuanced understanding of the processes and practices involved in giving and receiving care in families with a parent at the end of life may bring into focus the moral deliberations involved in relational practices between a young person and a parent at the end of life. This in turn may illuminate the manner in which moral identities are shaped through both subjective experience and the enactment of socially constructed norms of child/parent, carer/cared for, approaching adulthood/approaching death.

Finally, a sociological approach to the exploration of family care in the context of end of life care supports an examination of the ways in which policy discourses and practices in end of life care may help or hinder young people in getting by when they have a parent at the end of life. For example, a sociological perspective opens up to scrutiny the question of whether the framing of care as a burden might lead to a 'troubling of the 'normal'', and to a presumption of damage that overlooks young people's resistance and potential for recovery, as well as the diversity of experiences that may be obfuscated by the application of a dominant 'harm story' (Ribbens McCarthy et al., 2013: 11).

2.4. CONCLUSION

The significance of family care at the end of life is consolidated in a policy discourse and practice aimed at securing a 'good death' by promoting the home as the ideal place of death. Research on the role of family carers and on the practice of family care at the end of life has focussed on adult dyads; little is known about young people's involvement in family care, or about the complexity of the shifting dynamics of care between family members when a parent is dying. The dominance of a psycho-oncological construction of care has presented caring for a family member as a burden that generally results in negative outcomes for the carer. There is less understanding of care as a relational practice and as an everyday expression of the interdependency of family members. Further research is needed to understand the ways in which advanced parental illness impacts on the everyday lives of all family members, especially young people, but also on how living with dying is experienced and understood in and through everyday family life.

Research on young people living with a parent at the end of life has focussed on the psychological burden imposed by advanced parental illness on young people, and on the cognitive and behavioural strategies young people adopt in coping with parental illness. Living with a parent at the end of life has been constituted as a troubling breach of the normative construction of childhood as a protected space, but little attention has been given to the active involvement of young people in repairing and reconstructing everyday family life in this context. A social policy discourse on young carers has rarely been applied in end of life care, but presents similar limitations with regard to the positioning of young people as passive victims of their family context and the polarisation of the interests of young people and adults who are in need of care.

I have argued that sociological research on young people living in difficult circumstances offers a framework for generating new insight into the everyday lives of young people with a parent at the end of life. A

sociological perspective takes into account the interdependencies in relationships between family members and supports an enquiry into the meanings young people attach to care. Rather than setting out with the assumption that living with a parent at the end of life is an inevitable cause of damage to young people, a sociological approach offers scope to explore how the on-going challenges and changes associated with parental illness are incorporated into the everyday family lives of young people, and how young people make sense of their own lives in this context.

In this literature review I have identified gaps in the existing knowledge and understanding of young people's experiences of living with a parent at the end of life, and proposed that a sociological lens offers the potential to explore young people's experiences from a perspective that may lead to a new understanding of living with advanced parental illness. In particular, I have identified a lack of nuance in current understandings of 'family' and of 'care' in the literature on family care at the end of life, which may serve to obfuscate the experiences of young people and limit our understanding of the processes and practices that constitute family care for someone who is dying.

In view of the potential significance of notions of family and care in understanding the experiences of young people with a parent at the end of life, in the following section I review key theoretical developments in the sociology of family and of care in order to identify and elucidate the theoretical constructs I apply to interrogate the accounts of young people in the current study.

2.5. THEORETICAL FRAMEWORK

The following sections review the main theoretical developments in the sociology of family and of care and summarise the key propositions with regard to these terms that are applied in the current study. I begin by considering the concept of family.

2.5.1. Family

Ribbens McCarthy (2012) draws attention to the pervasive power of the notion of family in our everyday lives and in the language we use to talk about our relationships with significant others. Similarly, Mason (2008) examines our enduring fascination with ideas of kinship, and with the various forms through which kinship is negotiated and expressed. In referring to 'family' or 'kinship', these researchers allude to a debate amongst sociologists on how our most meaningful experiences of human connectedness are manifest and understood. Sociologists have also questioned and examined the utility of the concept of family for understanding the personal, social and political significance of intimate relationships (Edwards and Gillies, 2012; Gabb and Silva, 2011). Family has thus become a contested terrain in both research and in public policy.

This exploratory study both applies and interrogates the notion of family in seeking to understand young people's experiences of living with a parent at the end of life. By utilising the concept of family, I am locating the study in the research literatures on family care and on everyday family lives in changing and challenging circumstances. However, I acknowledge that whilst family may constitute an important dimension for understanding young people's experiences of living with a parent at the end of life, the meaning of family in this context should not be taken for granted. I have already discussed how end of life care policy and practice has defined the role of the family carer in terms that effectively exclude the experiences of many people who care for someone at the end of life, including young people. One aim of the current study is to address this gap by adding to our understanding of the meaning and experience of family in the everyday lives of young people in this context.

The purpose of this section is therefore to set out the theoretical understanding of family I apply in this study. I begin with a brief summary of the main developments in sociological theorising with regard to family.

2.5.2. Meanings of family

Gillies (2003) outlines the development of three perspectives in sociological thinking, in which family is characterised by:

- Breakdown and demoralisation
- Democratisation and egalitarianism
- Continuity and enduring power relations

The first perspective emerged from the response to a largely feminist critique of a structuralist theory of family established prior to the 1970s. The structuralist model advocated by Parsons (1956) saw the nuclear family as ideally adapted to fulfilling the purpose of economic production and consumption in a capitalist society and the gendered division of labour as an inevitable response to the requirements of modern industry. Feminist academics challenged the division between public and private spheres endorsed by this model, and drew attention to growing empirical evidence of violence and abuse towards women and children as an unexceptional feature of family life (Barrett and McIntosh, 1982; Oakley, 1974). At the same time, commentators from the New Right presented rising divorce rates and changes in family structure as a major cause of societal breakdown, which they attributed to women placing their own needs above those of the family (Murray, 1990).

A more optimistic interpretation of changes in the structure and composition of family emerged from the work of post-structuralists, who were interested in human agency and the construction of the self in late modernity. Giddens (1991) characterised the self as reflexive; i.e. freed from the constraints of traditional roles, individuals create themselves through their day to day decisions in a process he referred to as biographical construction. From this perspective, rather than being governed by norms of obligation and reciprocity, family relationships are based on mutual understanding through negotiation; a form Giddens called the 'pure relationship'. The pure relationship is sustained only in so far as it provides personal satisfaction, with each participant acting

reflexively as an agent of change. This 'intimate democracy' is extended to children, who whilst subject to parental authority, retain a status of in principle equality (Giddens, 1999).

Similarly, Beck and Beck-Gernsheim (1995) developed a model of family based on the theoretical principle of 'individualisation' in which individuals become authors of their own life scripts. They argued that as traditional social ties are weakened, the search for intimacy becomes central to the creation of meaning, and that the parent-child bond in particular acquires significance due to its reliability and durability in comparison to adult relationships.

Critics of the post-structuralist approach to family point to the lack of analysis of factors such as ethnicity and class, and the mechanisms by which the 'lifestyle choices' of individuals engaged in a project of the self continue to be limited by such factors. Also, Giddens' model of the democratic family obscures the legally defined and institutionalised context in which parent-child relationships are situated, whilst Beck and Beck-Gernsheim present a somewhat idealised view of parent-child relationships. Feminist researchers suggest that such relationships are sometimes characterised by ambiguity and ambivalence in place of bonding and unconditional love (Finch and Groves, 1983).

Charles et al. (2008) argue that the scope for 'biographical construction' in and through family is bounded. They draw on Bourdieu's concept of 'habitus' to explain the continued strength of embodied and often gendered moral rationalities around care in families and the continued discursive power of the 'normal family'. The consistency, continuity and endurance of traditional ideals of family and moral absolutes such as 'putting children first' have been demonstrated in a number of empirical studies (Duncan and Edwards, 1999; Ribbens McCarthy et al., 2000).

A further strand of research on meanings of family has drawn attention to forms of intimacy such as same sex relationships, in which negotiated commitments are formed in the absence of the constraints imposed by

normative assumptions of gender relations in the context of the nuclear family. Weeks et al. (2001) suggest that such 'families of choice' may take many diverse forms and are characterised by an emphasis on fluidity and flexibility and on establishing new ways of 'being family' through everyday 'experiments in living'.

Morgan (1996) has taken a different approach to theorising the increasingly diverse forms of family more prevalent in the late twentieth century. Instead of conceptualising family as a set of biological or social ties more or less reflective of the idealised, normative family, Morgan expanded on the notion of family as an interactional process, and focussed on what individuals do in their everyday lives to create and sustain family. Morgan introduced the idea of 'family practices'; a fluid and variable set of routines and activities that define family, as opposed to co-residence, kinship or marriage. The family practices approach emphasises the agency of individuals in co-constituting family and locates family in a biographical, as well as a cultural and historical context. Family is thus reframed as something we *do*, rather than something we *are*.

Morgan's notion of family practices provides a potentially useful way of exploring the complexity of everyday family life in changing and challenging circumstances. The interest in family members as social actors who perform family in their everyday lives enables a scrutiny of when and how the doing of family changes in response to parental illness, and the involvement of young people in reconstituting family through new or altered configurations of family practices.

This necessarily brief overview of the main developments in sociological thinking with regard to family introduces some of the key concepts I have drawn from the literature and applied in this study. The following propositions indicate how I have approached an understanding of family, and offer a theoretical framework for investigating how family both shapes and is shaped by living with a parent at the end of life.

2.5.3. Propositions about family

Family as physical presence/absence

To begin with, it is worth noting that in everyday usage family is generally not understood as a theoretical abstraction, but is experienced in and through our physical presence in relationships with others as parents, children, siblings, partners, spouses. These relational identities are formed and maintained with the presence of the other, even when they are physically absent. Indeed, recent research suggests that a form of embodied relationality may persist with significant others even after their death, in which the living may continue to feel 'bound up' with the dead (Ribbens McCarthy and Prokhovnik, 2014: 31).

The notion of family as a physical presence/absence may shed light on how everyday family life is affected by the physical decline of a parent at the end of life from the perspective of the young people in this study. A young person's affective response to the physical transformation of their parent and the potential for increased physical intimacy through the provision of care may disrupt the boundary of the parent-child relationship and impact on the relational identities of family members in the present and into the future. The extent to which everyday experiences of family are troubled by living with the presence of dying, and the significance of the juxtaposition of 'presence' and 'absence' in young people's everyday lives are potential areas of interest for this study.

Family as everyday practices

I am drawn towards Morgan's (1996) concept of 'family practices' as a means of understanding how family is actively constructed and maintained in difficult circumstances. Scrutiny of the 'little fragments of daily life' (1996: 190) that constitute family practices may help to reveal ways in which family changes and adapts when a parent is at the end of life, which practices are significant for the maintenance of family during this time, and why. Family as everyday practices also draws attention to young people's agency in shaping family, and may help to reveal how

young people get by in and through the everyday doing of family when a parent is at the end of life.

Finch (2007) added the notion of display work to Morgan's framework, arguing that family practices need to be recognised and understood by others in order to establish their legitimacy as signifiers of family. Finch suggests there may be degrees of intensity in display work, and outlines circumstances where the need for display becomes greater as a consequence of changes in family circumstances. The potential threat posed to family by the life-limiting illness of a parent may represent a situation where display work is increased. Evidence of display work in young people's everyday family lives with a parent at the end of life may therefore add to our understanding of doing family in these circumstances, and to the doing of family in general. As Almack (2008) suggests, 'The working out of family practices in families which do not fit conventional frameworks may make all the more explicit the more common efforts and processes undertaken by all families that are often taken for granted and thus less visible' (2008: 1186).

Family as an ideal

Gillis (1996) distinguishes between 'families we live with' and 'families we live by'; with the former relating to family as it is lived out in everyday lives, and the latter encompassing idealised myths, beliefs and images of family as it exists in the individual and collective imagination. Family as an ideal draws on culturally and historically embedded meanings of family as a close, cohesive unit (Gillis, 1996). Daly (2003) argues that the persistence and tenacity of these images 'plays a very important role in managing the tensions, conflicts, and disappointments that arise in the course of living *with* a family' (2003: 778).

The empirical study by Wilson et al. (2012) of young people living with parental substance abuse provides some evidence of the symbolic power of the idealised family in shaping the experiences of young people in difficult circumstances. The accounts of young people in the Wilson et al.

study illustrate the importance of being able to claim a coherent family narrative to offset the pain of living in a family that does not conform to the ideal. Being attentive to traces of the idealised family within and beneath young people's accounts of living with a parent at the end of life may shed light on whether and how the sense of loss and longing for family as an ideal is experienced by young people in this context.

Family as socio-political discourse

Sociological approaches to family have pointed out that family lives are constituted in the context of broader social and political narratives and that these narratives are culturally and historically specific (Morgan, 1996). Socio-political discourses of family draw on the notion of the idealised family, sometimes in order to emphasise the absence of socially validated features of family life; for example, in the discourse on 'troubled families' (Ribbens McCarthy et al., 2013). The potential for such discourses to amplify or minimise young people's attempts to deal with disruption in their everyday family lives is of interest to this study.

Contributors to the Ribbens McCarthy et al. (2013) edited book 'Family Troubles' have explored the nuanced concepts of 'troubled', 'troubling' and 'troublesome' families and the processes by which families may be categorised as such, or shift between categories depending on the lens through which their everyday lives are viewed, and by whom. Public and policy discourses on young people living with life-limiting parental illness and young carers potentially overlap with the discourse of troubled families, in that each emphasises the risk of negative outcomes for young people continuing into adulthood (Aynsley-Green, 2012; Hounsell, 2013). The extent to which the private troubles of young people living with a parent at the end of life may be interpreted through the socio-political discourse of troubled families may shed light on the governance of boundaries between fluid and shifting meanings of family and illuminate how family at the end of life is constituted in both the private and public domain.

Having identified the key propositions with regard to meanings of family I draw on to inform an understanding of young people's experiences of living with a parent at the end of life in the current study, I turn now to the complex and contested notion of care.

2.5.4. Care

Care is a ubiquitous feature of our everyday lives; present in the verbal and visual landscape we inhabit, in the cultural products we create and consume, and in the relationships we develop and maintain throughout the life course. Yet the precise definition of care remains contested. Theorists have attempted to describe and explain what it means to care, often fragmenting care into a series of dichotomies, for example:

- giving / receiving care
- caring for self / caring for others
- care as action / care as emotion
- paid / unpaid care
- personal / institutional care

In this section I briefly consider meanings of care, particularly care that takes place in the context of family, and outline the theoretical approaches to care that have informed my understanding of young people's experience of living with a parent at the end of life. I do not aim to provide a comprehensive overview of developments in care theory, but to highlight concepts that have resonated with my reading of the literature on young carers and on family care at the end of life, and to consider how these may be applied to interpreting the accounts of young people in this study.

2.5.5. Meanings of care

The complex and multifaceted view of care found in contemporary literature can be traced back to the work of feminist researchers from the 1970s onwards, who were concerned with highlighting the significance of

women's unpaid labour in the home to understandings of the labour market, the family and the welfare state (Oakley, 1974; Rowbotham, 1973). However, the emphasis on family care as work; in particular as gendered activity performed by women, and the value of care as unpaid labour, tended to obscure the significance of care as a sentient activity; often involving emotions as well as actions (Graham, 1993).

Hochschild's (1983) research on workers in the service sector drew attention to the effort involved in managing emotion in order to perform a required function, encapsulated by the term 'emotional labour'. Finch & Grove's (1983) edited collection of essays was influential in shifting the focus away from family care as domestic labour towards an understanding of care based on both the emotional and practical investment made by women in the maintenance of everyday family lives. These forms of caring were distinguished as 'caring about' (feeling an affinity and affection for someone) and 'caring for' (servicing their needs) (Ungerson, 1983).

Developments in the concept of care from a sociological perspective emphasised the importance of material, structural and ideological processes in shaping meanings and manifestations of care. An alternative framework for understanding care focussed on care as a form of moral reasoning and ethical practice. This built on the work of feminist philosophers, psychologists and political scientists and came to be known as an ethic of care.

An ethic of care takes as a starting point the notion of care as a universal experience and emphasises the commonality of dependency and vulnerability as part of the human condition. Earlier iterations were modelled on the mother-child relationship as a primary example of the centrality of care in everyday life. Writers such as Noddings (1984) and Ruddick (1989) proposed that the mother-child relationship shapes the child's social identity and forms a blue-print for subsequent relationships and experiences of care. Whilst this approach has been criticised as

promoting an essentialist and individualistic concept of care (Mason, 1996), the intention was not to confine care to the private domain of the family, or to elevate an over-romanticised view of motherhood to the status of moral theory. Instead, feminist theorists sought to use women's experiences of mothering as a model for understanding the ethical basis of relationships in other contexts; from interpersonal relationships, to relationships between groups, service users and providers, and individuals and the state (Kittay, 1999).

Writing from an ethic of care perspective, Fisher and Tronto (1990) have defined care as:

> 'A species activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web' (1990: 40).

Fisher and Tronto's definition of care seeks to provide a framework for encompassing all caring activity, not only care provided in the context of the family, and it is therefore deliberately broad in its scope. Tronto (1993) explains that the intention was to move beyond restrictive notions of care as a discrete activity that takes place between two people in a dyadic relationship to incorporate an understanding of care as a situated process; 'the concern of living, active humans engaged in the process of everyday living. Care is both a practice and a disposition' (1993: 104).

Tronto (1993) proposes that the practice of care can be understood as comprising four phases, each of which is characterised by a corresponding ethical value or moral principle, which together form a disposition to care:

1. *Caring about* – being *attentive* and alert to the existence of need
2. *Taking care of* – assuming *responsibility* for responding to need
3. *Care-giving* – acting with *competence* to meet need

4. *Care-receiving* – acting with *responsiveness* to care received

(1993: 127)

Tronto's framework has enabled an ethic of care to be applied to the analysis and evaluation of care in different contexts. For example, Brannelly (2006) adopts this four phase approach to examine the care enacted between practitioners and people with dementia, leading to an analysis of the impact of professional detachment on achieving an integrity of care.

Other writers have developed and expanded Tronto's framework to include moral principles important to the practice of care such as trust (Sevenhuijsen, 2003) and respect (Engster, 2007). An ethic of care has therefore continued to develop as a dynamic approach to understanding and interpreting care as a relational and a moral process manifest through care as both an activity and a disposition.

A final iteration of the meaning of care I will consider here is that of 'caringscapes' and 'carescapes' (McKie et al., 2002). This framework emphasises the importance of time and space to understanding relationships of care. The caringscapes approach is generally applied to an analysis of informal care, and incorporates many of the elements of an ethic of care; care is understood as a relational activity guided by an ethical orientation to work out the proper thing to do in a given context (Bowlby, 2012). What this concept adds is a focus on the significance of places and spaces in which care takes place, and the work involved in plotting a route through the changing landscape of possibilities and opportunities for care; 'routes that are influenced by everyday scheduling and by combining caring work through paid work and the paid work of carers' (McKie et al., 2002: 904). In addition, caringscapes include a temporal dimension, as care relationships may be affected by changes that take place over the time frame of a day, or a life course.

The concept of 'carescapes' further developed this notion to draw attention to the material and social resources that shape the caringscape

terrain. An interest in the resources available to care is, however, not unique to this approach, and has been embedded in understandings of care since the earliest attempts at defining the concept.

The various interpretations of the meaning of care I have outlined here resonate in different ways with my reading of the literature on family care at the end of life and on young people's involvement in caring for a family member, and offer some potentially useful conceptual tools with which to approach an exploration of young people's experiences of living with a parent at the end of life. In the following section, I outline a number of propositions with regard to care I intend to employ in this study and draw attention to some of the issues they may help to address.

2.5.6. Propositions about care

Care as a practice

In describing care as a practice, Tronto (1993) states:

> '…it is an alternative to conceiving of care as a principle or as an emotion. To call care a practice implies that it involves both thought and action, that thought and action are interrelated, and that they are directed towards some end' (1993: 108).

Whilst Tronto was seeking to distinguish an ethic of care from notions of care as maternal instinct, the omission of emotion from this interpretation of care as a practice does not reflect the work of feminist researchers on care in the context of the family, where the significance of care as both physical and emotional labour is underscored.

Haugen (2007) writes, 'it is difficult to imagine children caring in families without adding feeling to their activities' (2007: 656). This would appear salient to an exploration of young people's experiences of living with a parent at the end of life; therefore, I have chosen to adopt a view of care as a practice more akin to Mason's (1996) notion of care as 'sentient activity and active sensibility' (1996: 27). Based on her empirical work on family and kin relationships (Finch and Mason, 1993), Mason (1996) writes, 'our

analysis implies that feeling and thinking may be important components both of the activity of care and the relational process through which it develops' (1996: 26).

The term 'sentient activity' is used to draw attention to the practice of feeling and of thinking as active, albeit often invisible activity and therefore sometimes unacknowledged or underestimated. 'Active sensibility' describes the process of feeling a responsibility towards someone else; 'a relationally and socially constructed 'predisposition' to draw a connection between self and specific others' (Mason, 1996: 31). This understanding of care as a physical, rational *and* emotional expression of a contextually bounded connectivity has the potential to support an exploration of young people's experiences of living with a parent at the end of life; therefore in referring to care as a practice, or to care practices, it is this interpretation I will draw on. The notion of care as a practice defined in this way will enable an investigation of the significance of physical, rational and emotional acts of care to young people's understandings of their experience of living with a parent at the end of life.

Care as relational

Early feminist research on care drew attention to the delivery of informal care in the family as a gendered form of labour; i.e. as a material product of the structural and ideological construction of the family. Within health and social policy literature on family care, there has also been a tendency to view care as a form of physical and emotional 'work', and to quantify and classify both the amount and the nature of the work undertaken by family carers.

Whilst this research has influenced the development of a policy discourse around the need for greater recognition of the role of carers and young carers, I have argued that it is based on a notion of the right to protection as a commodity that can be distributed between autonomous and independent 'patients' and 'carers' according to their needs. Barnes

(2011) suggests that the commodification of rights within this model obscures the relational sensibility and interdependency of care relationships between family members; for example, a young person with a parent at the end of life may be both a provider and a receiver of care in relation to their parent(s), sibling(s) and other significant people in their everyday lives.

The notion of care as a practice and a disposition, both relationally and contextually situated, offers the potential to explore the processes involved in fostering connections between a young person, a parent who is at the end of life and other family members as parental illness progresses. In this context, care is not an outcome or product of living in difficult circumstances, but is a means of making tangible and opening up to interpretation the lived experience of difficult circumstances for both the young person and their family members. The concept of care as a relational practice; a practice of acting, thinking and feeling within and between 'family', will therefore be applied in this study.

Care as moral

Drawing on Tronto's (1993) meaning of care, Brannen and Heptinstall (2003) write, 'Care is a form of ethical activity and moral thinking' (2003: 185). They refer to the work of Finch and Mason (1993) to argue that care provided by family members is no longer understood as an absolute duty, but is continuously negotiated in the context of particular circumstances and relationships. Williams (2004) states:

> 'Moral reasoning based on care informs the way people attempt to balance their own sense of self and the needs of others. What it means to be a good mother, father, grandparent, partner, ex-partner, lover, son, daughter or friend is crucial to the way people negotiate the proper thing to do. In working through their dilemmas, certain practical ethics emerge for adults and children, which enable resilience, facilitate commitment and lie at the heart of people's inter-dependency' (2004: 74).

An understanding of care as an ethical practice brings into focus the moral deliberations involved in relational practices between a young person and a parent at the end of life, and illuminates the process by which moral identities are shaped and enacted through negotiating 'the proper thing to do' in and through young people's everyday family lives.

Care as gendered

As has been discussed, early interpretations of care emphasised the meaning of care as 'women's work'; drawing on either women's 'natural' proclivity to care, or on the structural and ideological forces that shape the significance of women's domestic labour .

Later developments in the conceptualisation of care focus on care as a universal, human activity, but continue to scrutinise the way in which care practices and the moral deliberations that inform relational identities may be differently interpreted and applied according to the gender of key protagonists, alongside other structural attributes such as race, (dis)ability and class (Ottosdottir and Evans, 2014; Philip, 2013).

The literatures on family care at the end of life and on young carers have also suggested that there may be variations in the way that the burden of care is born by women and men (Grande et al., 2009; Morris et al., 2015; Rose and Cohen, 2010), although many empirical studies do not refer to gender at all, but apply the term 'family carer' or 'young carer' in a manner that suggests care is gender neutral.

This study will adopt the approach that the experience of living with a parent at the end of life is likely to be impacted upon by gender, along with factors such as race and class. The gender of the young person, the parent who is ill, and that of siblings or other significant family members may impact upon the relational experience of living with a parent at the end of life, and on the moral deliberations and practices of care between family members in these circumstances.

Care as bounded by space and time

Care as a practice takes place in a spatial and temporal context. In particular, for young people living with a parent at the end of life, family care will often be located in the home and may be incorporated into the young person's daily routine, or may necessitate changes in routine. As I have discussed, current end of life care policy places significant emphasis on dying at home as a measure of quality in end of life care (Pollock, 2015), although the impact on young people's experiences of living with a parent at the end of life has not been investigated. The way in which young people use space and time in and outside the home, and any changes that may have occurred as a consequence of living with parental illness are therefore of interest.

Research on young carers has suggested that young people's expectations of the future will be affected by their caring responsibilities, and that some young people may defer making decisions about the future as a consequence (Hounsell, 2013). The time-limited nature of a young person's relationship with a parent at the end of life is particularly significant for this study, and raises questions with regard to how young people think about the future when to do so may entail an acknowledgement that their parent will no longer be with them. A concept of care that is sensitive to the importance of space and time is therefore relevant here.

Care as linked to resources

Based on data from the Longitudinal Survey of Young People in England[7], Hounsell (2013) reports that being a young carer is strongly associated with factors such as having a lower family income, parental unemployment and lower levels of maternal education. This suggests that for young people who are involved in family care, both the process and the experience of providing care is likely to be impacted upon by the level

[7] https://www.education.gov.uk/ilsype/workspaces/public/wiki/LSYPE for more information

of material and social resources available to the family. In addition, Hounsell goes on to point out that young carers are no more likely than their peers to come into contact with support services, in spite of a social policy environment intended to promote recognition of, and responses to young carers' needs.

End of life care policy and practice advocates increased support for family members, 'including children, close friends and informal carers of people approaching the end of life' (Department of Health, 2008: 14). A view of care that takes into account the material and social resources that influence family members' experiences of providing care and the support available to family members will enable the impact of this policy to be evaluated, particularly from the perspective of young people living with a parent at the end of life.

In this section, I have explored key theoretical developments in sociological approaches to interrogating the concepts of family and of care; concepts that are highly significant to developing an understanding of family care when someone is at the end of life. By drawing on theoretical propositions derived from the sociological literatures of family and care, I aim to develop a more nuanced account of young people's everyday family lives in the context of living with dying.

In the following chapter, I present the research questions for the current study and the research methodology and methods I have adopted in this exploratory investigation of young people's experiences of living with a parent at the end of life.

CHAPTER THREE: METHODOLOGY

3.1. INTRODUCTION

This study is an exploratory investigation of the everyday meanings and practices that constitute family life for a young person when they have a parent at the end of life. Consistent with a view of young people as agentic subjects (Mayall, 2000) who contribute to the production and maintenance of everyday family lives in and through their decisions and actions (Smart et al., 2001), the study privileges the perspectives of young people themselves.

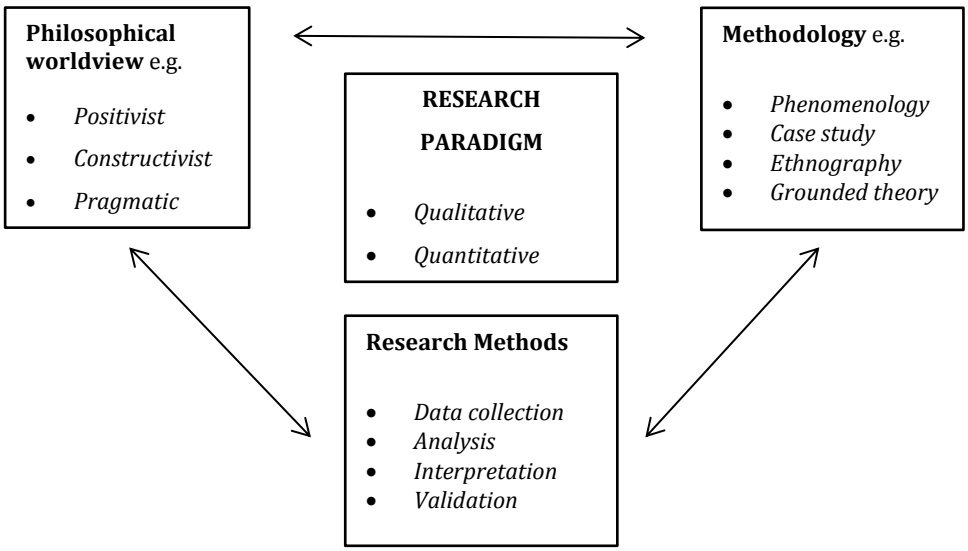
In-depth, qualitative interviews were used to generate accounts of living with a parent at the end of life from 10 young people aged 13-21. In addition, young people were asked to identify significant others for inclusion in the study. Five adults were subsequently interviewed (four parents and one partner of a young person). Young people's accounts were analysed using the voice centred relational method based on the work of Gilligan (1982, 2003). Accounts of significant others were used to support a multiple perspectives approach to understanding the meaning and practice of the key relational concepts of family and care in young people's everyday lives.

Young people in the current study are positioned as experts in their own experience, and as responding to events in their lives 'building on whatever set of assumptions, constructs, or expectations individuals already use to build their everyday worlds upon' (Ribbens McCarthy, 2007: 295). However, it is acknowledged that the conceptual, social and material tools available to young people in making sense of their everyday worlds are influenced by the contexts in which young people's lives are lived; therefore the study considers young people's experiences in the context of the family and significant relationships, and in the light of broader social discourses relating to family care at the end of life.

In this chapter, I outline the research questions and the research strategy employed in the current study. In particular, I explore the issues and challenges raised by conducting research on a sensitive subject with a population generally constituted through the research governance process as being vulnerable. Mason (2002) describes a research strategy as, 'the logic by which you go about answering your research questions' (2002: 30). Similar to an explorer's map, the research strategy charts the path taken from the identification of research questions to data analysis, indicating the route chosen and the conceptual and practical tools employed along the way.

I use Cresswell's (2014) framework for research (Figure 2), in which he depicts the interconnections between epistemology, methodology and methods, as a means of structuring the chapter. The intention is to bring to light the 'dynamic, active and reflexive process' (Mason, 2002: 32) of strategic thinking that informed and shaped the development and implementation of the current study. I begin by presenting the study aim and outlining the research questions I set out to explore in order to clearly signpost the starting point on my research journey.

FIGURE 2: A FRAMEWORK FOR ANALYSIS



(adapted from Cresswell, 2014: 5)

3.2. RESEARCH AIM

The aim of this study is to explore the family lives of young people who are living with a parent at the end of life.

Drawing on the review of the literature and on identified gaps in the existing research knowledge and understanding of young's people's experiences of living with a parent at the end of life, the study questions are:

- How do young people experience everyday family life when they are living with a parent at the end of life?
- What practices and processes help or hinder young people in these circumstances in getting by?
- How do young people experience care in the context of a family with a parent at the end of life?
- How do young people who are living with a parent at the end of life make sense of this experience in relation to their own lives?
- To what extent are young people's accounts of living with a parent at the end of life influenced by familial and wider social narratives of family life in the context of end of life care?

The study questions are designed to investigate how young people's everyday experiences are shaped by the context of living with a parent who is dying. The questions enable an exploration of the meanings attached to family and the significance of care practices for young people with a parent at the end of life. The focus is not on care as a set of measurable and independently verifiable activities but as a relational process, experienced and interpreted by the young person within a nexus of socially constructed familial and cultural narratives and norms. As such, the study questions aim to elicit the subjective experiences of a young person and of significant others who shape the context in which the young person's experience takes place.

Having presented the research questions, I return to Cresswell's (2014) framework for research to begin my elaboration of the research strategy, starting with a brief description of the overall approach, or research paradigm, which forms the core of the framework and provides the foundation upon which the study is built.

3.3 RESEARCH PARADIGM

The current study is exploratory in its overall aim, and is designed to respond to a number of questions that predominantly focus on *how* young people experience living with a parent at the end of life. Harper (2012) writes, 'Qualitative methods are, in general, better at developing rich descriptions of phenomena and processes' (2012: 84); therefore, a qualitative approach will be applied to the design of the current study.

Punch (2014) points out that a research paradigm is, 'necessarily philosophical in nature. In general, paradigm means a set of assumptions about the world, and about what constitute proper techniques and topics for inquiring into that world' (2014: 14). Thus, research paradigms are concerned with the ontological, epistemological and methodological foundations of research, and in ensuring consistency across these fundamental components of an inquiry.

In the next section I consider the first two of these components, which together constitute what Cresswell (2014) refers to as the 'philosophical worldview' from which the research strategy is devised. The researcher's philosophical worldview acts as the lens through which the research problem is scrutinised and the research questions are brought into focus, and its exposition is therefore important in understanding the decisions taken in the process of formulating the research strategy.

3.4 PHILOSOPHICAL WORLDVIEW

Carter and Little (2007) write, 'It is impossible to engage in knowledge creation without at least tacit assumptions about what knowledge is and

how it is constructed' (2007: 1319). For Doucet and Mauthner (2008), the essential process of ontological and epistemological enquiry that must precede any research endeavour can be summarised by the question, 'What can be known and how?' (2008: 399). In shaping our research questions, we must first consider whether they are consistent with our assumptions concerning the nature of the phenomena under investigation and the type of knowledge it is possible to elicit.

The research questions posed by the current study indicate that the overall research strategy will be informed by an interpretivist epistemology. In contrast with a positivist epistemological position, where knowledge is regarded as testable experience that can be verified by reference to an objective reality, an interpretivist approach regards knowledge as intersubjectively constructed and located in a particular physical, temporal and relational context (Benton and Craib, 2001). The study's focus on family and on care as the young person's subjective experience of relational practices that are contextually bound by time and place reflects a formulation of knowledge as individually and socially constructed, and therefore, as a product of interpretation.

However, it need not be assumed that the young person themselves can only be understood as a product of discursive practices. Some researchers writing from a feminist perspective have taken issue with the postmodernist account of the individual as both situated in, and constituted by, social discourses because of the challenge to notions of self-reflexivity and autonomy that this implies (Benhabib, 1992). Nevertheless, the assumption of a unitary and agentic subject does not sit easily with a feminist analysis of individual experience as subject to the formative power of gender(ed) discourses. Doucet and Mauthner (2008) attempt to resolve this dilemma by drawing attention to the concept of the 'narrated subject'. In the following section, I will consider how the idea of the narrated subject can act as a bridge between the ontologically 'real' subject and the epistemologically interpretive knowledge of subjective experience generated through the research encounter.

3.4.1 The narrated subject

Doucet and Mauthner (2008) refer to the work of Somers (1994) in proposing that, 'an effective way of working out the impasse between constructed or critical subjects is the concept of a 'narrated subject'' (2008: 402). They argue that it is through narratives that we come to make sense of the social world and to construct our social identities; such that the narrated subject is both active and constantly changing.

As an example, they offer Stanley's (1993) reflective account of writing a diary in which she records her daily struggle to continue 'knowing' her mother whilst she is dying, and therefore moving towards a state in which 'her self-hood was unravelling' (1993: 403). Stanley proposes that the narrated self is both 'grounded in the material reality of everyday life' and constituted in relation to other narrated selves. Agency is seen to exist in the construction and reconstruction of these narratives, and as such, 'subjectivity is present in the subject's use of language, and not only in language itself' (Doucet and Mauthner, 2008: 403).

Doucet and Mauthner (2008) emphasise that whilst the researcher may set out to examine the research subject's 'real', material and relational self through the research process, it is the subjective construction of the narrated self that is available for scrutiny during the research encounter. They conclude:

> 'There may be something 'beneath' or 'behind' or outside narrative: nevertheless, all we can know is what is narrated by subjects, as well as our interpretation of their stories within the wider web of social and structural relations from which narrated subjects speak' (2008: 404).

In relation to the current study, the concept of the narrated subject enables an exploration of the subjective construction of a young person's experience of living with a parent at the end of life, whilst recognising the significance of the material and structural context in which this experience takes place. Although it may not be possible to encounter an

authentic self, a focus on the narrated self brings into the analytical frame the young person's agency in constructing a narrative of family life. The young person is thus positioned as a social actor, acting both within and upon the material, temporal and relational context of family.

The contradiction inherent in the 'unknowable' narrated subject suggests that a philosophical position for the current study is required that can bridge the positivist – interpretivist dichotomy. The following section will consider the potential of a critical humanist approach to provide a philosophical foundation for this research.

3.4.2 Critical humanism

Plummer's (2001) auto/biographical approach offers an effective framework for constructing an understanding of what can be known about a narrated subject through a research enquiry. Plummer describes the benefits of a close, contextualised study of individual lives in all their complexity as a response to 'an interminable tension between the subjectively creative individual human being acting upon the world and the objectively given social structure constraining him or her' (Plummer, 2001: 4).

According to Mason (2002), a concern with people as social actors and with auto/biography as a means of conveying individual experience in a meaningful way are essential elements of research conducted from a humanist perspective. The 'critical' element of critical humanism reflects an interest in the impact of structural factors on 'the webs of meaning through which lives get organised' (Plummer, 2001: 264), and the importance of carrying out reflective research which acknowledges the researcher's position in relation to the social discourses that shape the individual narratives of both the researcher and participants.

This philosophical position is congruent with an interpretive practice that is sensitive to both the 'hows' and the 'whats' of lived experience; that is, 'centred both in how people methodically construct their experiences and

their worlds and in the configurations of meaning and institutional life that inform and shape their reality-constituting activity' (Gubrium and Holstein, 2003: 215). I suggest that this form of critical humanism offers a philosophical approach that is consistent with the questions posed by the current study.

In this section I have identified and outlined the concept of the narrated self as the focus of inquiry for the current study. The study is based on the philosophical position of critical humanism, which supports an interpretive approach to generating knowledge but is sensitised to the potential significance of structural factors in shaping the conditions and resources available for the creation and maintenance of subjective meanings in the lives of young people who are living with a parent at the end of life. In the following section, I will consider the next component of Cresswell's (2014) framework for research; the research methodology.

3.5 RESEARCH METHODOLOGY

According to Cresswell (2014), research methodology can be understood as the process by which the analysis undertaken and the conclusions reported can be philosophically and theoretically linked to the research questions posed. My aim here is to identify and elaborate on my selection of a multiple perspectives methodology as being commensurate with a qualitative research paradigm, and with the philosophical worldview of critical humanism as a lens through which to view the narrated self.

In deciding upon a methodology for the current study, my initial proposal was to employ a multiple case study design. According to Yin (2014) a case study, 'Investigates a contemporary phenomenon (the 'case') in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident' (2014: 16). This definition appeared to fit the current study, with the young person's experience of family life constituting the case, bounded by the context of a family with a parent at the end of life. However, Yin emphasises that case study methodology involves the use of multiple sources of data to trace

converging lines of enquiry following the principle of triangulation (2014: 120). Here, it became apparent that the path of the current study was beginning to diverge from a case study approach, both epistemologically and for ethical and practical reasons.

Epistemologically, the notion of triangulation, or even convergence of evidence, suggests that there is a 'truth' that the inquiry is seeking to uncover. Instead, when the subject of inquiry is a narrated subject, the act of narration is inevitably contextually bound, such that data obtained through an encounter with a narrated subject can only ever be understood as a product of that event. Furthermore, the requirement to obtain multiple sources of data from a young person about their experience of living with a parent at the end of life raised ethical concerns about the response burden placed on young people who are living in difficult circumstances. Certain forms of data collection, such as observational methods, were potentially intrusive, and the use of repeat measures was problematic in the context of the limited life span of the ill parent.

In considering the study's focus on the meaning and practice of family and of care in young people's accounts of living with a parent at the end of life, it became increasingly apparent that the perspectives of family members other than the young person may be useful, not in terms of 'triangulating' a young person's narrative, but in order to provide a context within which the young person's account could be understood. In seeking to identify a methodology that could incorporate the use of multiple perspectives whilst remaining within the epistemological framework of the study I was drawn back to the sociological research literature on family, where the collection of data from more than one family member has been prevalent. In the following section, I explore the application of a multiple perspectives approach in research on family and outline my rationale for selecting this methodology for the current study.

3.5.1. Multiple Perspective Studies

Within family sociology, the use of individual or group interviews with two or more family members has developed as a means of gaining insight into a practice, process or relationship from the multiple perspectives that constitute an understanding of family (Ribbens McCarthy et al., 2003). For family sociologists, multiple perspectives research has enabled a move away from empirical practices that substitute one individual as a proxy for family based on a normative construction of the nuclear family as a cohesive unit (Finch and Mason, 1993). Instead, a multiple perspectives approach reflects a conceptualisation of family as a complex set of practices embodied by individuals and 'predicated on shared and situated relationships of care' (Murray and Barnes, 2010: 534). Multiple perspectives studies have been used to deepen and challenge notions of what is meant by family in a wide range of contexts (e.g. Almack, 2005; Baldassar, 2008; Song, 1998).

Concurrently, there has been a growing interest in the use of a multiple perspectives methodology by researchers in health care, particularly in relation to studies of family care and of family practices with regard to health (Coyne et al., 2012; Mellor et al., 2013). For researchers in health care, multiple perspective studies, particularly those that include patients and their family or paid carers, can 'generate a richer understanding of needs and experiences' and provide recommendations for improving services and support (Kendall et al., 2009; 196).

Whilst the utility of a multiple perspectives approach has increasingly been recognised, the methodological literature on how to conduct a multiple perspectives study is still underdeveloped, although important contributions have been made to addressing questions of recruitment (Lewis, 2009; Mellor et al., 2013), data collection (Seymour et al., 1995; Morris, 2001), ethical conduct (Forbat and Henderson, 2003) and analysis (Ribbens McCarthy et al., 2003; Warin et al., 2007).

The rationale for applying a multiple perspectives approach in the current study was to understand more about a young person's perspective by exploring ways in which the narrated self is shaped by its encounters with other narrated selves. My aim was to examine how young people constitute their everyday experiences of living with a parent at the end of life in relation to significant others in the family, and how the language and themes present in young people's accounts are reflected or refracted by different family members. In this way, the relationships of care between family members and the negotiations and practices that constitute care relationships become a lens through which everyday family life for young people with a parent at the end of life can be viewed.

It is important to note that the intention here was not to construct, 'a 'more complete' version of family lives' (Ribbens McCarthy et al., 2003: 3), but to consider 'the complexities, contradictions, and tensions' (Song, 1998: 115) that are revealed in young people's accounts of living with a parent at the end of life when viewed in the context of the family. The multiple perspectives approach applied to this study therefore privileged young people's perspectives whilst taking into account those of other family members. The following sections elaborate on how I proposed to identify family members for inclusion, and explain my decision with regard to choosing a method for generating multiple perspectives.

3.5.2. Multiple perspectives: Who?

The methodological literature on multiple perspective studies has tended to focus on research involving dyads; for example, couples (Mellor et al., 2013), parents and children (Harden et al., 2010) or siblings (Song, 1998). The process and practice of conducting research with more than two family members is relatively unexplored, although some landmark empirical studies in family sociology have been carried out using this approach (e.g. Finch and Mason, 1993; Smart et al., 2001).

In the current study, whilst the main participants were young people with a parent at the end of life, I chose not to prescribe who else to include,

since one of my objectives was to explore young people's experience of family, and therefore it was important not to pre-empt any judgement over who is identified as a family member. Instead, I proposed to invite young people to nominate significant others whose perspectives they wanted to include in the study. This decision supported the study ethos of privileging the voices of young people and recognising them as active participants in their lives.

Furthermore, I aimed to expand the boundaries of care implied by the dyadic model usually employed in research on family care by including two or more family members in addition to the young person where possible. In practice, the process of nominating significant others often differed from that set out here. I will describe the process of study recruitment in practice and consider the reasons for this divergence later in this chapter (section 3.8.2.).

3.5.3. Multiple perspectives: How?

I chose to use individual interviews to elicit the experiences of young people and family members in this multiple perspectives study. In deciding on interviews as the method of data collection, I was mindful of the experience of researchers such as Evans and Becker (2009) and Lambert et al. (2013) who found that young people, particularly those who are over the age of twelve and living in the UK, prefer to 'just sit and chat' (Lambert et al., 2013: 609). The use of more creative methods appeared to be less appealing for this group; in Evans and Becker's (2009) study of young people caring for a parent with HIV/AIDS in Tanzania and the UK, young people from Tanzania took up the opportunity to produce drawings and photographs to describe their family lives, whereas young people from the UK perceived the life story book and camera as "extra homework' and a demand on their time' (2009: 75).

The use of more creative methods often necessitates a conversation with the young person in order to elicit the meaning of any drawings or photographs etc. produced (Angell et al., 2015). This adds an extra stage

to the data collection process, thereby increasing the demand on participants; something I was keen to avoid given the challenges young people in the current study may already be facing in their everyday lives.

In addition, I met with some young people at a very early stage in the research process in order to help inform the study design. At the invitation of a local young carers' project, I attended an activity day during the school holidays, where five young carers aged 9–13 shared their views on how to engage young people in a research study on living with a parent who has a serious illness. A brief report on the outcomes of this discussion can be found in Appendix 1. These young people expressed a preference for individual, face-to-face interviews as a means of talking about the experience of providing care for a parent. One young person commented, 'You need to see how the person reacts to what you're saying – erm, if they're shocked or anything'.

This consultation suggested to me that as well as knowing that they can 'just sit and chat', young people want to be able to assess the researcher's ability to 'just listen' to their stories. The young carers I spoke with appeared to intuit research as a negotiated relationship between a researcher and a participant, with research knowledge as the emergent product of this exchange. An interview or 'conversation with a purpose' (Burgess, 1984: 102) is perhaps the simplest and most direct means of embodying this dynamic relationship.

Jansen's (2015) study of young people in residential care offers an interesting perspective on the use of interviews in research with young people who are often problematised as troubled or troubling to others. Jansen suggests that 'situations involving interactions between these young people and adults often become sites for measurements, assessments, evaluations and treatment' (2015: 33). In contrast, a research interview offers the young person a chance to speak without being interrupted, challenged or placated, and in doing so, positions the

young person as someone with a valuable story to tell; one that is worth listening to in all its complexity and ambivalence.

A research interview in which both the participant and the researcher actively engage in shaping the encounter by listening and responding to the words and actions of the other encourages the generation of research data in a manner that is ethically mindful, particularly when dealing with a sensitive subject. An exploratory study by Holland et al. (2010) of the lives of young people who are looked after by a local authority found that, whilst young people were offered a variety of methods for data collection, 'young people tended to share more intimate experiences or personal perspectives when alone with a researcher' (2010: 365).

The data for this multiple perspectives study was therefore generated through individual, face to face interviews with young people and their significant others. This approach supports the study's aim to provide a descriptive account of the subjective experiences of young people living with a parent at the end of life. It is also appropriate for a study in which young people may divulge sensitive information, warranting the attention of an actively listening and ethically mindful researcher. Furthermore, a research interview enables a young person to adopt a subject position as an expert in their own lives, confirming the value of their experience and offering a way of being that may be experienced as 'more liveable' (Jansen, 2015: 28) than the available alternatives.

The decision to carry out interviews with young people living with a parent at the end of life, and potentially with their parent who is at the end of life, raised a number of ethical issues for the conduct of the study that required careful deliberation. In the following section, I explore these issues in more detail and outline my response to the anticipated ethical concerns generated by the study design and methodology.

3.6. ETHICAL ISSUES

Opinions on what counts as sensitive research vary (Dickson-Swift et al., 2008). Nevertheless, the combined context of the research topic (living with a parent at the end of life) and the perceived vulnerability of participants (young people) is an example of a research area that may be deemed particularly sensitive. However, as Bowtell et al. (2013) point out, even the most thorough planning cannot anticipate every circumstance that may arise during the research process, and unaccounted for ethical contingencies remain inevitable. The ethical conduct of sensitive research must therefore involve a combination of careful preparation, sensitivity to the occurrence of 'ethically important moments' (Guillemin and Gillam, 204: 265) and a reflexive response to issues that arise in the field.

Whilst I have provided an overview of the ethical issues identified during the planning phase of the study in this section, my intention has been to take an ethically mindful stance to the overall conduct of the study and the production of this account; therefore I have incorporated further reflections on ethically important moments throughout this report in order to better reflect the dynamic process of conducting ethical research.

3.6.1. The vulnerability of participants

The construction of young people as vulnerable is associated with a developmental paradigm of childhood, in which the child is viewed as physically, cognitively and emotionally incomplete and therefore in need of adult supervision and protection (Wyness, 2006). However, although existing social and legal structures generally situate young people as subordinate to adults, the rights of a child to express an opinion and for that opinion to be taken into account are enshrined in the United Nations Convention on the Rights of the Child (Cree et al., 2002). This has stimulated a proliferation of research aimed at giving a voice to young peoples' experiences, and a recognition that the right to protection must be balanced by the right for young people to be heard.

People at the end of life are regarded as vulnerable in the research process because of their experience of serious illness and the impact this may have on their capacity and competence (Walker and Read, 2011). Addington-Hall (2002) questions the assumption of vulnerability in people at the end of life, stating, 'People with a limited prognosis are still people, with decision-making capacity (unless proved otherwise) and, as far as we know, the same views as other people as to the value to the community of research participation' (2002: 221). The principle of autonomy in choosing whether to take part in research should, therefore, apply equally to this group.

I was mindful that fatigue, anxiety and the limited availability of time are factors that are likely to impact on both adults at the end of life and young people who may be taking on additional caring responsibilities. Therefore, I ensured that participants were aware that their involvement was voluntary and that they could withdraw from the study at any point. Consent was regarded as a process, rather than as a single event, in order to take into account any changes in the physical or emotional condition of a participant. Sensitivity with regard to the location, timing and length of research interviews was applied, and interviews were rescheduled when necessary.

3.6.2. The potential for distress

Deep-seated cultural sensibilities around dying and death in the UK tend to sharpen the scrutiny of research ethics committees charged with upholding the principle to 'do no harm' in the context of research on end of life care (Seymour et al. 2005). With regard to qualitative research based on in-depth interviews, researchers have noted a tendency for the notion of 'harm' to be conflated with 'distress' (Allmark et al., 2009; Gabb, 2010).

As Pollock (2012) points out, the biomedical paradigm that informs ethical decision-making by these bodies is largely at odds with the relational, negotiated ethics that guides the conduct of qualitative

research. Empirical studies have found that participants do not necessarily report the experience of becoming distressed as harmful, and may instead regard it as cathartic or beneficial in their attempts to make sense of their experience (Allmark et al., 2009; Jansen, 2015).

Whilst I did not wish to arouse distress for young people and others taking part in the study, I agreed with the stance that distress is not always experienced as harmful. This stance was largely supported by practitioners consulted during the early stages of study design, many of whom expressed the view that spaces for young people to voice the experiences and emotions that accompany living with a parent at the end of life are limited. The opportunity for young people to take part in a research study that may help to shed light on their concerns was therefore broadly welcomed even if in opening up the research space, I invited in distress.

I recognised the importance of remaining alert during the interviews to cues that a participant may not wish to continue with certain strands of their story, and I made on-going ethical judgements about lines of enquiry to pursue. All interviews were conducted whilst another adult known to the participant was on the premises, and I prepared an information sheet with details of relevant support services to hand out following each interview.

The possibility that I might experience distress as a result of listening to young people's stories was also considered. My own personal and professional experience helped me to feel confident that I would be able to deal with the emotional content of interviews. I had access to regular supervision from academics with expertise in research on dying and death, and a good support network of family and friends to draw on. I explore the process of conducting the research interviews and the presence of emotion in the interview space in more detail in section 3.8.3. of this chapter.

3.6.3. Securing informed consent

The task of ensuring that potential participants are fully cognisant of the parameters of a research study is generally facilitated through the use of a participant information sheet. Research ethics bodies tend to favour a cautious approach in approving language for use in participant information for end of life care research (Gardiner et al., 2010). The emotional weight of terms such as 'end of life' must be recognised and the potential to cause distress even if an individual is aware of the prognosis must be acknowledged.

Research also suggests that it is not uncommon for people at the end of life and their family members to move in and out of awareness, or to avoid a state of open awareness of prognosis in order to maintain a degree of self-protection (Copp & Field, 2002; Richards et al., 2013). With this in mind, the study materials were developed and revised in consultation with young people and practitioners from a young carers' service to ensure that the research topic was introduced appropriately and sensitively. The study used the language of '*Living with a parent who has a serious illness'* but included the question *'Do you have a parent with a serious illness who is not going to get better?'* in the information sheets used in participant recruitment (Appendices 2 and 3).

I also decided that a young person would be approached about the study in the first instance by a practitioner who was already in contact with them and/or their family. In line with Notko et al. (2013), I regarded practitioners as professionals who could act as 'safety nets' for the young person, and whilst I believed that this strategy would better enable a sensitive introduction to the research, it carried implications for site selection and participant recruitment, as I go on to discuss (section 3.8.).

Tisdall et al. (2009) caution that the notion of providing signed consent may be unfamiliar to young people, who have less experience of formalising their relationships through the use of such explicit devices. Following the initial introduction to the study by a practitioner, I

therefore met with all potential participants individually in order to explain and negotiate this process with them[8]. In practice, the process of securing the informed consent of individuals, and particularly of young people in the context of family, raised questions about the presumed autonomy of the research participants I revisit later in this chapter (section 3.8.).

3.6.4. Dynamics of the researcher-participant relationship

An early concern during the planning stage of the study was how to ensure young people felt comfortable to discuss sensitive aspects of their family lives in a research interview. The device of the interview situates the researcher in a position of power in relation to the interviewee, since the researcher asks the questions and controls the direction of the interview 'conversation' (Allmark et al., 2009). The potential for the imbalance of power inherent in this encounter to be exacerbated is particularly pertinent to the conduct of research interviews with young people, who are already situated as less powerful than adults on account of their age (Valentine, 1999).

Self-disclosure on the part of the researcher has been suggested as one strategy for managing unequal power relations in a research interview (Reinharz and Chase, 2003). It is argued that the practice of sharing similar experiences with a participant positions the interviewer as an 'insider' and that the researcher's insider status builds rapport and empowers the participant towards more positive involvement in the research encounter. This perspective prompted me to question how much of myself and my own experiences I wanted to reveal to young people in the current study.

Whilst it is possible that claiming insider status may have enabled me to 'get alongside' participants and invite their trust, it also felt like a false claim; there are equally factors that positioned me as an 'outsider' in

[8] For young people under 16, their assent was sought only after the consent of a parent had been obtained.

relation to young people; age and gender being the most apparent. A review by Abell et al. (2006) of three interview studies involving young people concluded that it is difficult to ascertain precisely how participants position and construct interviewers. They observed that in sharing experiences, the interviewer often inadvertently exemplified differences in terms of other factors such as social class and education. Furthermore, self-disclosure could be seen to draw attention away from the participant and on to the researcher, and to suggest that the researcher has a greater entitlement to talk about the subject area than the participant. Abell et al. (2006) suggest that this is potentially confusing for participants, who generally understand the purpose of the research interview to be for them to provide new information to the researcher.

In her interviews with young people who had experienced domestic violence, Solberg (2014) chose to emphasise this interpretation of the participant's role. She writes:

> '...my strategy was to follow up particularly sensitive questions by reminding both myself and my informants about the basis for our conversation: that I lacked knowledge that they possessed and that I needed to learn from their experiences' (2014: 244).

Her stance is supported by Cree et al. (2002), who suggest that the ethical approach to dealing with power imbalances in the researcher-participant relationship is to recognise and acknowledge the young person as the expert in their own experience and therefore as a valid and valued participant in the co-production of knowledge.

I therefore decided that I would make time before and after the interviews for young people to ask me about myself and would respond openly to questions without pre-empting what young people may want to know. I also followed Phelan and Kinsella (2013) in trying to maximise the young person's sense of agency throughout the research process by offering them the choice of location, using the young person's own language and terminology during the interview, and ensuring that they

knew how to end the interview should they wish to. Further reflections on my experience of negotiating 'insider-outsider' positionality and power in the research process are included later in this chapter, where I discuss the process of recruitment.

In this section, I have described the process of identifying and responding to the ethical issues generated by this study. Whilst this was necessary preparation for undergoing a formal ethical review, it also increased my understanding of the ethical conduct of research as not only an exercise in meeting the requirements of a research ethics committee, but also as an on-going process of moral deliberation embedded in the relationships between the researcher and participants.

Guillemin and Gillam (2004) call for researchers to adopt a reflexive stance 'not only to issues relating to knowledge creation but also ethical issues in research' (2004: 275). This is particularly important in the context of research with young people in end of life care, where the duty of care towards participants who are living in difficult circumstances demands the reflexive engagement of the researcher in meeting the fundamental requirement of research to 'do no harm'.

3.7. METHODS

So far in this chapter, I have presented a rationale for employing a qualitative research paradigm founded on a philosophical worldview of critical humanism. I have discussed my decision to adopt a study methodology based on a multiple perspectives approach, and I have explained my choice of individual interviews as the method of data collection. With these methodological tools in place, the remainder of this chapter describes the process of transforming research theory into research practice; conventionally termed research methods. Research methods are the practical activities of research including recruitment, data collection and data analysis (Carter and Little, 2007). These activities will be discussed chronologically in the following sections.

3.7.1. Ethical Approval

The study was reviewed and given approval by a Research Ethics Committee (REC). Site specific approvals were obtained from NHS Research and Development Departments for all NHS sites. In addition to the study protocol, participant information sheets and study consent forms were submitted and approved. Tailored versions of study materials were produced for participants over the age of 16 (Appendix 2) and for participants less than 16 years of age (Appendix 3). A sample interview schedule was also approved (Appendix 4).

3.7.2. Study settings

The initial intention was to recruit study participants from the East Midlands region in order to facilitate data collection. I proposed to contact young people living with a parent at the end of life through young carers' projects and end of life care services as these services were likely to be in contact with eligible young people.

Two young carers' projects; one based in a city and one covering a large county, and two end of life care services; one based in a hospital and the other in a community setting, were identified as sites for recruitment. This strategy was designed to facilitate a broad exploration of young people's everyday experiences of family life with a parent at the end of life as set out in the research questions. However, it soon became apparent that these four sites would not generate a sufficient number of participants during the timescale for recruitment; therefore additional study sites were targeted as follows:

Young Carers' Projects

Using a national database held by the Carers' Trust, I sent an email to over 350 young carers' projects across the UK containing information about the study and asking for support with participant identification. This did not produce any response. A second email was sent out on my behalf by Professor Saul Becker, a leading expert in research and policy in relation

to young carers. Five projects responded asking for further information, but only one project was able to identify potential participants and was therefore added as a study site.

End of Life Care Services

I contacted twelve services who work with people in need of end of life care in the East Midlands over a three month period. Many of these services reported being reluctant to engage with the research study for a variety of reasons; for example:

- concern about the impact on staff time, sometimes related to staff shortages
- difficulty in identifying a lead professional who would take on the role of local collaborator as required by the process for gaining research approval in NHS settings
- concern about the sensitivity of the research in relation to young people's awareness of their parent's prognosis
- the service did not have specific records of children in a family, and even if they did, they may not record their ages
- the service was unlikely to be able to identify any eligible young people within the timescale of the study

Three Specialist Palliative Care Consultants working in hospice settings did agree to support study recruitment, and these three hospice sites were added to the study following completion of the relevant research governance processes.

I had considered recruiting young people through schools, but consultations with local head teachers indicated that school staff may not be aware of when a young person is living with a parent at the end of life until after the parent's death. Furthermore, head teachers reported that they were not confident pastoral support staff in schools would be equipped to provide adequate support to any young people who were identified via this route, therefore I chose not to pursue this option.

I also considered alternative sources of data to address the topic under investigation in the event that I was unable to identify any young people for inclusion; for example, recruiting practitioners who are in contact with young people with a parent at the end of life. However, this would have entailed conducting a different research study from the one I had set out to complete. Ultimately, although challenging, recruitment to the study was achieved within the ten month recruitment period. I return to a more detailed discussion of the difficulties of participant recruitment later in this chapter (section 3.8.), where I reflect on issues with the research process.

3.7.3. Identifying participants

A purposive sampling strategy was adopted whereby participants were selected on the basis of having experience of the event in question. Since this study aimed to explore the experience of young people living with a parent at the end of life, criteria were as follows:

Young person

In their review of research from within the 'new' social studies of childhood, McNamee and Seymour (2013) point out that many researchers continue to adopt inclusion criteria for young people based on the notion of their developmental stage or competency. Working within a model of childhood as socially and historically delineated, I chose to use the socially defined concept of an educational stage as an inclusion criterion.

The study included young people aged 13-21 as this is the age at which young people are required to engage in a series of deliberations through the education system regarding their plans for the future, and therefore this constitutes a significant period of transition for young people. The extent to which living with a parent at the end of life impacts on young people's sense of their own lives both in the present and in the future is an area of interest for this study.

Parent at the end of life

A parent was defined in accordance with Section 576 of the Education Act 1996[9] as:

- all natural parents, whether they are married or not
- any person who, although not a natural parent, has parental responsibility for a child or young person
- any person who, although not a natural parent, has care of a child or young person (having care of a child or young person means that the child lives with and is looked after by that person, irrespective of what their relationship is).

As set out in the key terms for the study (Chapter 1: section 1.1.3.), 'at the end of life' was defined as 'likely to die within the next 12 months'.

At the start of the recruitment phase, I met with all local collaborators and attended staff team meetings to discuss the study and respond to any questions or concerns. During these meetings and in subsequent conversations, I emphasised that in order to meet the study criteria, the young person needed to be aware of their parent's prognosis. This was both for ethical reasons, as I did not want to risk disclosing information the young person may not have been aware of, and also for epistemological reasons. The study aimed to explore young people's experiences of living with a parent at the end of life in the assumption that they are aware of this circumstance, and that their narratives are shaped in part by this awareness.

It was agreed that practitioners would identify young people whom they understood to be aware of their parent's prognosis. However, I accepted that the young person may have shifted out of a state of open awareness (Copp and Field, 2002) at the point of interview, and that this ambivalence towards parental prognosis may constitute one aspect of living with a parent at the end of life.

[9] Available from http://www.legislation.gov.uk/ukpga/1996/56/section/576

Significant Other

Young people who agreed to participate in the study were invited to nominate one or more family member(s) to be included in the study. Young people were informed verbally and in the participant information sheet that a family member may include a parent, a sibling, a grandparent or 'someone else who is important to you'.

Number of main participants

The question of how many participants to include in a qualitative study depends on a number of factors (Baker and Edwards, 2012). The overall purpose of the study is a primary consideration. This is an exploratory study of a hard to reach group in an under-researched aspect of family care at the end of life. The study aimed to elicit in-depth information on young people's subjective experiences, and whilst I was not aiming for 'representativeness', I hoped to include sufficient participants to reflect a variety of experiences.

Many of the 'expert voices' in Baker and Edward's (2012) review draw attention to practical factors such as the availability of time and other resources, and highlight the importance of striking a balance between the quality of analysis and interpretation and sample size. With this in mind, I aimed to recruit 10 to 12 young people. I considered that this would be sufficient to include a range of ages, family compositions, parental diagnoses and factors associated with socioeconomic status, whilst enabling an in-depth analysis of all interview transcripts.

3.7.3. Recruitment

Practitioners at the eight study sites (Table 1) were given information packs to use when they identified a young person[10] who met the study criteria. If the young person wanted more information about the study, they were invited to contact the researcher, or their consent was given for

[10] For young people <16 years, the parent was always approached in the first instance at each stage of the recruitment process and meetings took place with the parent present except for the research interview.

me to contact them. I arranged to meet with the young person to discuss the study and answer any questions. I explained that the young person would be invited to nominate others to take part. If the young person wanted to participate, I proceeded to complete the consent form, or else a second meeting was arranged to enable the young person to talk with family members in the first instance.

At the second meeting, I checked that the young person still wanted to take part in the study before completing the consent form. Significant others were identified and the process of consent was repeated with them individually. I agreed a time for conducting an individual interview with each young person and significant other. Sometimes interviews took place immediately after the signing of consent forms, but on other occasions I returned to complete the interview at a later date. Most participants chose to meet me at their home. I met with two young people at a voluntary project they attended, and with one young person at their university. I ensured that another adult known to the young person was in an adjacent room as a safeguard for both the young person and myself.

On two occasions practitioners identified more than one young person in a family as eligible for the study, and therefore some families had more than one main participant. The recognition that more than one young person may be in a position to provide an account of living with a parent at the end of life better reflects both the experience of family life and the theoretical concept of family as a nexus of interdependent relationships underpinned by practices of care. Therefore, I decided to allow for more than one main participant from each family to be included where appropriate.

3.7.4. Study participants

A total of ten young people and five significant others from six families were recruited for the study. Table 1 illustrates the number of participants recruited by each study site. Individual study sites are not

referred to by their proper names in order to better protect participant identities.

TABLE 1: PARTICIPANT RECRUITMENT BY STUDY SITE

Study Site	**No. of young people identified**
Young Carers' Project (South City)	0
Young Carers' Project (County)	0
Young Carers' Project (North City)	2
Hospital Palliative Care Service	0
Community Palliative Care Service	1
Hospice (North)	4
Hospice (Central)	2
Hospice (South)	1
TOTAL	**10**

Four of the five significant others were parents of a main participant; three of the four parents interviewed had a life-limiting illness. One significant other was the partner of a young person included in the study.

In one family, each young person also acted as the significant other for their sibling as no other family member wished to take part. However, multiple readings of a narrative in order to address different research questions is consistent with the overall approach to this study; therefore I decided to regard each main participants' interview transcript as serving this dual purpose. One young person did not choose to identify a significant other, but was included in the study as a main participant. Otherwise, each young person's experience is considered in the context of their 'family', whether this is represented by a sibling, a parent or multiple family members. Further demographic information on the young people is presented in Table 2.

I have chosen to present information about the young people who participated in the study in a way that does not explicitly reveal the

relationships between the young people and their significant others or explicate the composition of the six families from whom the main participants are drawn. This decision has been taken in order to better protect the identities of participants. One issue with multiple perspectives studies involving family members is that family members may recognise each other in research reports, even after any identifying characteristics have been removed (Forbat and Henderson, 2003). By not providing information about family groupings, my aim is to reduce this risk.

TABLE 2: DEMOGRAPHIC DETAILS OF THE MAIN PARTICIPANTS

Gender	Three participants in the study are young women; seven are young men
Age	The age of the young people in the study ranges from 13 to 21. The average age is 17.3 years.
Education	Eight of the young people are in full-time education. One young person was about to commence an apprenticeship, and one young person had taken a break from university but was planning to return. In total, three young people attend university; all are in the first generation of their family to pursue higher education.
Ethnicity	Nine young people were born in the UK; one was born in the Indian sub-continent.
Household composition	Five young people live with both biological parents; four of these young people also have siblings living at home. Five young people live with their ill parent only; three of these young people have no siblings living at home
Parental illness	Nine young people are living with a mother at the end of life. One young person's father is at the end of life. In nine families, the parental illness is cancer. In one family the parent has motor neurone disease.

This decision does not compromise the integrity of the multiple perspectives approach; young people's accounts are still scrutinised in the light of the accounts of significant others, and in my discussion of the research findings, I indicate where the perspectives of family members have been used to expand on the interpretation of a young person's narrative. In Table 3, I introduce the ten young people and five significant others who participated in the study by the pseudonyms I have used throughout this report.

TABLE 3: STUDY PARTICIPANTS

Young People	**Family members**
Dan	Anna
Ellie	David
Elliot	George
James	Kathleen
Jay	Shelley
Jess	
Joe	
Lauren	
Luke	
Matt	

3.7.5. Data collection

An individual face to face interview was carried out with each study participant. I used a semi-structured approach beginning with a broad question, 'Tell me about your family', and using an outline interview schedule as, 'a set of starting points for discussion, or specific stories' (Mason, 2002: 62) (Appendix 4). The intention was to enable participants to shape the direction of their narrative and to introduce divergent themes whilst ensuring that areas pertaining to the research questions were addressed. Interviews were digitally recorded and varied in length from 25 minutes to one hour and 20 minutes.

At the end of each interview, I explained what would happen next with the interview data and gave participants an opportunity to ask questions or comment on the interview process. I offered young people information on further sources of support. None of the participants chose to take a copy of this information. Participants were also asked if they would like to receive a report of the research findings following completion of the study. Nine of the ten young people requested a study report.

I transcribed each interview as soon as possible after the event, adding my own reflections on the process to a research diary. Participants' personal details and identifiers were removed during transcription and all study documents were stored securely on a password protected database or in a locked cabinet in accordance with university regulations.

3.7.6. Data Analysis

The philosophical and methodological framework for the study called for an interpretive and reflexive approach to analysis. The aim was to enable a reading of the text that brings into focus Doucet and Mauthner's (2008) narrated subject, actively constructed in relation to others and shaped by the social and cultural narratives that inform this activity. Doucet and Mauthner (2008) advocate the use of Gilligan's 'voice centred relational method' (Gilligan et al., 2003) as a means of achieving this aim. The voice centred relational method involves multiple readings of an interview transcript in order to illuminate different aspects of the narrated subject as it emerges through the research encounter.

I was drawn to this analytical approach following Edwards and Weller's (2012) reflection that the voice centred relational method both draws attention to the participant's subjectivity and produces 'a particular analytic ontology' in which the researcher is placed *alongside* the participant and their social reality, rather than *looking at* them. The notion of standing alongside the young person spoke to my concern with placing the young person at the centre of this enquiry and co-constructing an account from their vantage point, rather than that of a detached

observer. An analytical procedure that ensured my reading of the data remained close to the young person's perspective maintained the emphasis on the young person as a social actor and offered a means of getting beneath any 'surface noise' in the interview that can act to distort the interpretive process. Young people may have little or no experience of talking about themselves in the context of a research interview (Smart, 2006), and it is possible that the manner in which they relate their experiences in this context may sometimes mask the meaning of what is being said. The voice centred relational method may therefore be especially appropriate for sensitive research studies involving young people, as I go on to discuss.

Following Doucet and Mauthner (2008), I carried out four readings of each young person's transcript, focussing on a different facet of the narrated subject each time as follows:

First reading: Who is telling what story?

During the first reading of each transcript, the aim was to capture *what* the young person said about their experience of living with a parent at the end of life, 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 (Riessman, 2002) such as an interest in recurring words, imagery, characters and plot.

The 'whats' and 'hows' of each young person's account were summarised in an individual 'story' written for each participant. This facilitated the identification of initial themes which were transferred onto a spreadsheet and added to after reading each participant's account. The individual stories and emerging themes were shared with supervisors during regular meetings, along with extracts from my research diary tracing my reflections on the interviews. These meetings provided an opportunity for on-going and reflexive discussion of the interpretive process. The discussions also informed the grouping of themes under broader headings

related to the overarching research questions on young people's experiences of family life and of care. My aim in combining themes from young people's individual accounts was to reveal the commonalities between young people's experiences and to draw attention to differences.

Second reading: Who does she think she is?

The second reading of the text was designed to elicit the ontological narrative of the young person through the production of an 'I poem'. The purpose of the I poem was to trace how the young person spoke about herself and how she positioned herself in her narrative of family life by extracting from the text all statements involving the use of the first person pronoun. These were then transposed in the sequence in which they occurred in the form of a 'poem', which was arranged into a series of stanzas to reflect changes in the subject matter or the 'voice' of the participant. Extracts from young people's I poems are provided in Table 4 as exemplars of this method.

TABLE 4: EXTRACTS FROM I POEMS

Jay	**Lauren**	**Ellie**
If I live with someone else I can't live with someone else I can't live with my Dad. I get annoyed with my Dad I am seventeen I can live by myself If I want, I'll do it If I want to do it, I'll do it	I'm lucky I have the friends and the family I know that some people won't I'm lucky I wouldn't be able to go out I think I could do it without I don't mean a break from Mum, I just mean a break	I used to have a counsellor I don't have her anymore I always go to my friends When I hear things I tell them I have my friends I go in my room Sometimes I'm sitting there I'll just cry I'm sitting there I'd sit and think I'd go and meet up with my friends

The generation of an I poem condensed the text into a powerful and sometimes intense precis that, in being centred on the conscious, sentient and active young person, was particularly effective at revealing the experiential core of their account of family life. Doucet and Mauthner (2008) describe how the I poem can be used to highlight 'where the respondent might be emotionally or intellectually struggling to say something' (2008: 406). Given that young people were being asked to talk to an unknown researcher about the sensitive subject of living with a parent at the end of life in the unfamiliar context of an interview, it may be anticipated that some aspects of their experience would be difficult or painful to reveal. The production of an I poem sensitised me to aspects of the young person's narrative that may otherwise have remained more hidden beneath the surface and meant that I often returned to the transcript to trace the below the surface, emotional currents in their accounts.

For example, the above extract from Jay's I poem drew my attention to his concern with regard to where he might live when his Mum dies. On returning to his interview transcript, I noted how this concern fed into and reinforced his anxiety about being a 'burden' on his family; this is discussed in more detail in Chapter Five (section 5.4.1.). The construction of an I poem was therefore useful in that it focussed my attention on how the young person understands themselves as a fundamental part of the analytical process of producing my interpretation of their account. (Edwards and Weller, 2012).

This shift in my analytical position in relation to the young person enriched the interpretive process and helped to illuminate different aspects of the young person's subjectivity as revealed through their narrative of living with a parent at the end of life. However, the familial and social contexts in which young people live remain vital to an understanding of their everyday lives; therefore, I poems are arguably best viewed in the light of the young person's unabridged account. Otherwise, there is a risk that too much emphasis is placed on the notion

of the young person as an individual subject, rather than a narrated subject constituted in and through their relationships with others. For this reason, I have chosen to use only extracts from the young person's accounts in my reporting of the analysis in order that the context in which statements were made can be understood and evaluated.

Third reading: The relational self

In the third reading, the intention was to focus on how the young person talked about her relationship with others and herself in relation to others. Of particular interest to this study was the extent to which young people's family relationships are defined and described through the language of care, how family is mediated through the practice of care for young people, and the moral narratives associated with a relationality expressed through care; for example, stories of being 'a good child'.

The transcript of the young person and of each family member associated with the young person was analysed separately to ascertain how each participant talked about family and how care was described, and experienced by young people and their significant others. The language and themes with regard to family and care drawn from these individual readings were collated into a table for each grouping of a young person and their significant others. This enabled me to compare the accounts of young people and their significant others, to look for similarities and differences in how family and care was manifested and understood, and to consider how family life is experienced by young people *in relation* to those who are important to them.

Fourth reading: The structured self

During the fourth reading, I focused on the presence of broader cultural narratives in the young person's transcript; for example, tracing references to normative accounts of youth, parent/child relationships and a good death. Again, this process was repeated with the transcripts of other family members and relevant extracts were added to the family's table of themes, language and narrative threads.

Combining the readings

Each young person's account was analysed individually in the first instance. For each young person, application of the voice centred relational method enabled me to open a window on:

- their experience of living with a parent at the end of life,
- their sense of themselves as an agentic subject,
- their relationships and interdependence with other family members and
- the familial and cultural accounts that framed the presentation of their story.

During the second phase of analysis, I endeavoured to deepen my understanding of each young person's experience by considering it in the context of their family relationships. This involved examining the third and fourth readings of each young person's account alongside those of other family members in order to construct a multiple perspectives account of everyday family life. This account took into consideration the meaning, practice and moral significance of family and of care in the everyday lives of family members whilst remaining centred on the young person.

As previously stated, the purpose of listening to these multiple voices is not to seek out a 'truer' version of family life, or to combine accounts into a single, coherent family narrative. Instead, I was interested in the extent to which young people tell similar or different stories to those of other family members, using similar or different concepts and language (Ribbens McCarthy et al., 2003). A strength of the multiple perspectives approach is the potential it provides for a rich and multi-layered analysis of data. As Ribbens McCarthy et al. write:

> '…each twisting of the analytic kaleidoscope brings different issues into focus…revealing in all its complexity how issues of individual histories, shared family lives and standpoints of gender,

> generation, class and ethnicity are all interwoven in these related but individual accounts' (Ribbens McCarthy et al., 2003: 19).

Adopting the voice centred relational method to analyse the data from this multiple perspectives study enabled me to explore how a young person constructs their understanding of living in a family with a parent at the end of life in relation to significant others and to consider how the complexities, contradictions and tensions inherent in everyday family life have helped to shape young people's accounts.

Before I present the findings of the research, I consider in more depth the process of carrying out a multiple perspectives study on the sensitive subject area of young people who are living with a parent at the end of life. In particular, I explore my experience of where elements of the research in practice diverged from the pragmatic model suggested by Cresswell's (2014) framework for research and elaborated in this chapter. Research is a dynamic process, and it is not unusual for plans to be changed or practices reshaped in the journey from research protocol to completed study. Documenting these slips and shifts can help to reveal ethically important moments where the researcher is called upon to respond reflexively to dilemmas whilst maintaining the integrity of the research. Drawing attention to 'what went wrong' may therefore make more explicit 'what was right' and add to the explication of the research plan set out in the methodology chapter.

3.8. REFLECTIONS ON THE RESEARCH PROCESS

3.8.1. Recruiting young people

I had anticipated that recruiting young people to the current study would be challenging due to the sensitivity of the research topic. In addition, as I have discussed, the construction of young people as vulnerable within the research process raised issues for site selection and participant recruitment (Heath et al., 2007). Access to young people was mediated by key actors who were willing to support the research but who also acted as

'gatekeepers'; sometimes more than one set of gatekeepers needed to be approached (Agbebiyi, 2013). The building and maintaining of effective relationships with gatekeepers made significant inroads on my research time and required a host of 'people' skills beyond the ‘technical’ research skills I was expecting to require (Turner and Almack, 2016).

The initial recruitment strategy relied on the support of practitioners in two young carers’ projects. I had previously worked for an authority that provided funding to the projects, so was already known to these organisations as a representative of a body with some power and influence. I had also built up a relationship of trust with practitioners through collaborative work with young people and families during this time. Possibly, given previous connections, these local collaborators may have found it more difficult to decline to support study recruitment than if they had been approached by an unknown researcher. At the same time, I was dependent on practitioners to identify participants for the study.

This is illustrative of how the relational configurations of trust and power within the recruitment process are not straightforward or one dimensional, but are multiple and fluid (Edwards, 2013). Furthermore, the positionality of researchers and local collaborators may influence the process of recruitment in unanticipated ways. In my experience, a positive relationship built around my previous work identity proved to be a disruptive rather than a facilitative factor, in that it boosted my expectations of recruitment from sites where in practice, it was difficult for practitioners to identify young people.

In reconfiguring the recruitment strategy, I was concerned to approach sites where I felt the young people and their families would be supported throughout their participation in the research, and thus turned to specialist palliative care services. Both the sites and the practitioners I contacted were previously unknown to me. Here, it became apparent that the most effective strategy was the buy-in of consultants who then instructed nurse practitioners in their teams to approach eligible families

for the study. It appeared that these individuals had the authority within their organisational hierarchies to get participant recruitment moving. However, there was also some sense that they could strike a 'research bargain' (Bryman, 2008). In return for their input they sometimes made requests; for example, that I completed in-house training on the ethical conduct of research, even though the study had already been given ethical approval.

Once site access had been established, there were still challenges to address in operationalising access to participants. Gaining consultant approvals led to further layers of gatekeeping in terms of liaison with practitioners who made decisions regarding who to approach about the study (or not). It was thus important to invest in building relationships with practitioners in direct contact with potential participants. This entailed an on-going process of establishing trust through a series of face to face conversations with practitioners and attendance at team meetings. Engaging with gatekeepers in the field proved, as Crowhurst (2013) identified, an evolving process that had implications for which participants I was able to reach and the knowledge subsequently gained.

I found that although I talked through the participant information with practitioners, I had little control over the way in which practitioners chose to present the study to young people or their parents. Practitioners tended to adopt a cautious approach to identifying a parent as being at the end of life and chose to exclude young people if there was any sense of uncertainty. This may have been intended to protect family members from distress, and appeared to apply in particular if a practitioner was unsure of the extent to which a young person was aware of the prognosis. Excluding a young person from the study in this context could be regarded as ethical decision-making on the part of practitioners. However, it may also have served to extricate practitioners from the necessity of initiating a potentially difficult conversation to determine the extent of a young person's knowledge. This illustrates the way in which practitioners may exercise decisions to operationalise eligibility criteria

other than those agreed by the Research Ethics Committee. In this case, excluding young people with whom the practitioner had not had a prior conversation concerning their parent's prognosis meant that some young people who were eligible were not approached about the study, and therefore were not given the opportunity to decide for themselves whether or not to take part.

It is important to reflect that the actions and decisions of practitioners were not independent of the organisational environments in which they work, and were often a reflection of the way in which services are managed and delivered. For example, one of the external factors that appeared to influence practitioners relates to the categorisation of workers into 'children' and 'adult' service providers. This distinction sometimes resulted in young people with a parent at the end of life disappearing into the gap between the remits of these two types of service. Some palliative care practitioners identified themselves as adult service providers and expressed their lack of familiarity with talking to young people, and their concern about causing distress without necessarily having the means to offer support. In contrast, practitioners from young carers' services mostly worked with young people and often had limited contact with parents. Whilst they were experienced at supporting young people with very complex needs, young carers' support workers sometimes stated that they lacked the necessary skills to address the difficult subjects of dying and death. Thus, my view of practitioners as the potential providers of a 'safety net' was not as straightforward as envisaged.

Furthermore, the framing of sensitive subjects such as dying and death as taboo, and of young people as categorically distinct from adults, implies that a particularly specialist subset of skills is required to address such issues with young people, beyond the skills normally held by palliative care practitioners or young carers' support workers. This can both undermine the expertise of practitioners, and as my experience of study recruitment suggests, may lead to the marginalisation of young people as

participants in research. Perhaps more significantly, it may also act to exclude young people from being offered the help they may need.

3.8.2. Recruiting significant others

The identification of significant others was the second notable deviation from the recruitment schedule as set out in the research protocol. My intention that young people would be in control of this stage of the study process and would choose significant others to take part was seldom realised in practice. Young people appeared to encounter numerous difficulties in making an individual, autonomous choice of significant others, and in hindsight, I realised that this strategy was at odds with my understanding of young people as embedded in interdependent familial relationships.

As I have explained, young people who met the study criteria were initially identified by practitioners. Following identification by a practitioner, my point of contact for five of the ten young people in the study was the young person's parent. In some instances, it appeared that parents, in conversation with practitioners, had agreed who in their family should be included in the study before a young person was approached to take part. Parents not only acted as gatekeepers, but also on occasion as brokers of their family's involvement (Lewis, 2009), in that it was made apparent during my initial conversation with a parent that they expected to be interviewed as well as the young person. Whilst I adhered to my plan to meet with each young person individually and offered them the opportunity to decide who else to include, I recognised that it was probably difficult for young people to veto their parent's participation, should they have wished to do so.

One practitioner reported that a parent had asked for one of their children in particular to be included in the study. The young person had been identified as not having talked much about living with parental illness, and therefore the parent agreed that in opening up a space for discussion, the study may be of benefit to them. In the event, when I

visited the family, the young person, parent and other siblings were all present, and during our discussion of the study, another sibling asked to take part. It was only after this sibling spoke that the young person initially identified said they would like to be interviewed.

This example illustrates a number of issues with the recruitment of young people and family members to the study. Firstly, it appears that some young people may have been identified on the basis of 'hidden' criteria; in this case, finding it difficult to talk to their parents about their experiences. This raises the possibility that the young people who took part may differ in behaviour and attitudes from other young people who were eligible for inclusion, but did not take part (Lewis, 2009). Whilst I was not aiming for representativeness, this may have implications for the range of experiences I was able to access during the research and the knowledge gained. In this instance, the nomination of a young person who was reluctant to talk may have helped to counterbalance the inclusion of others who were very willing to talk about their experiences, and whose perspectives may therefore differ from those of young people who declined to take part.

Secondly, this example demonstrates how consent may be co-constructed between family members, rather than being the autonomous decision of one individual (Mellor et al., 2013). The point at which encouragement becomes coercion by family members is difficult to determine, and discussions that underlie the process of decision-making often take place in the absence of the researcher (Lewis, 2009). Even when the researcher is present, it is not always possible to fully address the impact of complex and multi-layered family dynamics. Whilst I spoke to each member of the family individually and assured them they did not have to take part just because another member of the family had agreed to, I cannot be certain as to whether these factors influenced the decision to participate. Furthermore, in accepting the sibling into the study as a main participant, I compromised my intention to enable young people to choose family members for inclusion.

Nevertheless, as study recruitment progressed it became apparent that some young people found it difficult to nominate family members themselves. In Lewis's (2009) study of parent-child communication about sex and sexuality, young people reported that it was hard for them to invite parents to participate in the research because it entailed initiating a conversation with parents on a sensitive subject; something they preferred not to do. The sensitivity of the research topic may have been a factor in the recruitment of family members by young people in the current study. Several young people said they were reluctant to approach their parent because the parent was too ill to take part. One young person struggled to identify anyone else whom they felt comfortable to approach. A number of young people lived alone with one parent and appeared to have a very limited number of close family members to call on. These factors influenced the relatively low number of family members eventually recruited to the study.

It appears that asking young people to nominate significant others may have placed them under a certain amount of pressure to meet an arguably unreasonable expectation. Researchers may therefore need to exercise caution in adopting this approach and recognise the limitations on young people's autonomy and agency when seeking to recruit family members for research purposes. The recruitment of family members to a multiple perspectives study is a messy business, and reflects the messiness and complexity of everyday family life. Decisions with regard to study participation demonstrate the interdependence of family members and highlight the relationality inherent in processes and practices that shape everyday family life.

Strict adherence to ethical governance procedures based on notions of independence and autonomy creates a tension for researchers interested in family lives. Drawing attention to such ethically important moments and the process of decision-making in the field may begin to shed light on how this tension can best be addressed.

3.8.2. Doing the interviews

As a practitioner, I have had considerable experience of meeting with young people and family members living in difficult circumstances, and I therefore envisaged that the conduct of the research interviews would be familiar and relatively straightforward to manage. In this section, I discuss my experience of the interview process to explore the implications of researcher positionalities for the unfolding of the research encounter and the generation of knowledge. I refer to positionalities here as possible ways of being that are offered and taken on by researchers (and participants) and draw on facets of professional and social identity.

I have previously described how the positioning of young people as experts in their own lives can open up a subjectivity through the research interview that is experienced by the young person as more positive than the available narratives of young people as 'troubled youths' or 'innocent victims' (Jansen, 2015). Similarly, the researcher is offered a position in relation to the interview that differs from that of therapist, social worker or advocate. I found that, emptied of the responsibility of trying to help, my position as a researcher enabled me to shift my focus away from the purely problematic aspects of a young person's life towards a deeper exploration of how the family lives of young people were being presented and what could be understood by the way a young person chose to communicate about themselves. Whilst being liberating on one level, this shift from practitioner to researcher entailed the adoption of a positionality of listener that was liminally more intense than my previous work roles.

Initially, I became aware of listening with 'double attention' (Becker et al., 2012: 293) to ensure that I was following the young person's narrative and maintaining an awareness of how the interview was progressing. Being aware of my own presence and role in the process was a third demand on my attention; I learned to allow silences and to resist interjecting to offer 'advice' based on my own professional or personal

experiences. As the interviews progressed, my sense that young people wanted someone to 'just listen' increased as I became aware that this was what the research interview appeared to provide. Whilst my position as a researcher meant that I was not there to intervene in the young person's experience of living with a parent at the end of life, I could give them my full attention; thus the position of active, attentive listener was one I tried to adopt and maintain. Equally, I was aware that this position enabled me to leave the field with a sense that I had offered the participants something in return for their involvement and in recognition of the difficult circumstances in which they were living.

Furthermore, I was mindful that young people's participation in the interview was sustained at their consent. Young people could (and sometimes did) refuse to answer a question, or could withdraw at any point. This was in contrast to my encounters with young people in my previous employment, which were generally for the purpose of assessment or the monitoring of an intervention. These were seldom truly 'voluntary' in that sanctions were often attached to a young person's non-compliance. As a researcher, I was thus positioned as reliant on the young person for any gains from the interview encounter to be achieved. This had the effect of disturbing the dynamics of power in the interview process, whereby any power attached to personal attributes such as my seniority (in terms of age) and educational experience was rendered less significant. Jensen (2015) argues that this positioning of the researcher in relation to the participant and the resultant influence on the balance of power is one reason why young people who do not engage with services may be willing to take part in research.

Thus, in negotiating the multiple configurations of researcher-participant positionalities, what is key is to recognise that both researchers and participants are embedded in, participating in and influencing relations of power. Here, I have tried to make explicit my experience of how the dynamics of power were affected by researcher-participant positionalities during the interviews I carried out for the current study.

Jansen (2015) also describes how the researcher is offered positions by people who are external to the research such as colleagues and friends. I found that when I first started talking about my research, both to academics at research conferences and to my own network of family and friends, it was a common experience to be asked how I managed to listen to such distressing life stories. It is possible that this assumption of distress being an inevitable feature of the research interviews was based on the questioner's own experiences of feeling overwhelmed by talking about dying and death. On reflection, I had to respond that young people did not appear to find the interviews distressing and neither did I. These exchanges raised another set of questions for me: had I done something wrong during data collection; for example, did I steer away from painful experiences? Had my own experiences of dying and death de-sensitised me to the presence of troubling emotions? In short, I felt exposed to a whole new research dilemma; how should I respond to the apparent lack of distress in my research interviews?

These questions challenged me to look again at my research methodology and data and to reflect on the manifestation of emotion in the research interviews. I found that far from being absent, the expression of emotion pervaded research accounts. Young people articulated their sorrow, anxiety, sense of helplessness and fear of the unknown, but they did not appear to be overwhelmed by these emotions. All had resources that they drew upon to support them in their everyday lives, and many spoke of their wish to simply get on with their lives. Consequently, as a researcher, I was not overwhelmed by distress, but came away from the interviews with a sense of the resourcefulness of young people and their determination to get by.

My experience of conducting interviews on a sensitive subject with young people assumed to be vulnerable has led me to question the construction of research in certain areas as sensitive and to ask, sensitive for whom? It may be that asking young people questions about difficult and challenging aspects of their lives is more troubling for researchers, practitioners,

parents and people responsible for regulating the ethical conduct of research than it is for the young people who are living out their responses, not in the concentrated confines of a research interview, but in the mundane routines of their everyday lives. Whilst gathering young people's accounts of living with a parent at the end of life may be sensitive work, it does not have to be distressing work; and without it, our ability to identify and alleviate distress in young people can only be poorer.

In this chapter, I have set out my research methodology and have reflected on some of the issues and questions raised during the unfolding of this research study. In the following chapters, I present the findings of the research according to the three main thematic headings; family, care and resources. In each chapter, I provide quotes from the accounts of young people as examples of the data and as illustrative of the material from which this interpretive account is drawn. In these quotes, an ellipsis (...) is used to denote missing text, whilst a hyphen (-) is used to indicate a pause. Identifying features have been removed, and all names are pseudonyms with the exception of my name, where I appear as the interviewer in extracts from young people's accounts.

CHAPTER FOUR: FAMILY

4.1. INTRODUCTION

This chapter explores young people's experiences of living with dying by examining how family is constituted in and through everyday life with a parent at the end of life. Young people's experiences of living with parental illness are embedded in the context of their everyday family lives and their relationships with significant others. The meanings and manifestations of family for young people therefore influence, but are also influenced by, living with a parent who is dying. In this way, understandings of family and of living with dying each constitute a lens through which the other may be viewed. In this chapter, I investigate the inter-relationship between experiences of family and of living with dying by considering how family is described and understood by young people with a parent at the end of life. I examine the practices that enable young people to maintain family during times of change, and explore the moral significance of changes in the meaning and practice of family for young people in this context.

As I discussed in the literature review (Chapter Two), some qualitative studies have explored changes in young people's relationships with family members when a parent has a life-limiting illness (Kennedy and Lloyd-Williams, 2009; Sheehan and Draucker, 2011). The impact of life-limiting illness on the relational identities of family members has also been addressed; in particular, for mothers who are ill. Previous studies illustrate the continuing importance of maintaining a moral identity as a good mother for women with a life-limiting illness when they have children, and offer examples of how the practice of mothering is reconfigured in and through everyday family life to take account of the limitations imposed by ill-health (Coyne et al., 2012; Elmberger et al., 2005; Stifler et al., 2008; Wilson, 2007). Fewer studies have considered how relational identities within the family may be affected for young

people, or have explored the moral consequences of living with a parent who is dying from the perspectives of young people themselves.

Previous studies suggest that when a parent is seriously ill, the routines and activities that constitute family life for young people may be disturbed (Helseth and Ulfsæt, 2003; Phillips and Lewis, 2015). For example, in her retrospective autoethnographic study, Pearce (2008) describes her adolescent experience of her mother's chronic illness and death as a 'rupture in an individual and familial reality' (2008: 133). For Pearce, parental illness is not only a threat to the parent, or to the young person's relationship with the parent, but is a catalyst for extraordinary change in the 'reality' of family. Yet theoretical and empirical work by sociologists indicates that family is a fluid and flexible construct, capable of adapting and enduring in the most troubling of circumstances (Ribbens McCarthy et al., 2013). Furthermore, young people's active involvement in redefining family practices and relationships has been interpreted as a potentially enabling factor in helping young people to 'get by' in difficult circumstances (Backett-Milburn et al., 2008: 461).

Ellis (2013) advocates thinking beyond a model of life-limiting illness and death as a rupture in order to 'connect the experience of dying with a sense of the mundane' (2013: 253). Her empirical study of family life at the end of life illustrates how mundane routines and everyday practices help family members maintain continuity and make sense of their experiences of disruption and change. In this chapter, I build on this approach to explore how young people make sense of their experience of parental illness in and through everyday family life when a parent is dying. I begin by examining the language young people use to describe and assess family relationships and the significance attached to meanings of family for young people when they are living with a parent at the end of life.

4.2. DESCRIBING FAMILY

Mason and Tipper (2008) draw attention to the creativity of children in developing an understanding of who they are related to and how. Acknowledging the fluidity of family and 'family-like' relationships they write, 'it has been increasingly recognised that kinship is not simply a 'given'. Instead, kinship is moulded and shaped through people's own family negotiations and practices' (2008: 441). In their empirical study, Mason and Tipper explore the language and processes children apply in assessing the significance of their relationships with others.

These processes may be particularly pertinent for children and young people who live in and with forms of family that do not reflect the normative ideal of the nuclear family. Mason and Tipper (2008) point out that it is not unusual to encounter complexity when seeking to define who counts as family, and that change is an ordinary feature of family lives. I have suggested that according to the available data, living with a family member who is dying is not an uncommon experience for young people in the UK (Parsons, 2011). Nevertheless, the manifestation of dying and death in everyday family life tends to be regarded as troubling, and as a threat to the meaning and experience of family for young people (Jamieson and Highet, 2013). Examining the language and processes young people adopt in constituting family in these circumstances can therefore shed light on how young people make sense of living with dying in their everyday lives.

In addition, whilst five of the ten young people in this study could be described as living in a normative family unit consisting of two (heterosexual) parents, five young people were living with one parent (mother). For three young people, their mother re-partnered following separation from their father; one young person lived consecutively with her biological father and two step-fathers. Other relatives (grandparents, aunts, siblings) are described as moving in and out of the young person's home and are part of the 'ordinary complexity' of everyday family life

(Mason and Tipper, 2008: 443). In working out who belongs to their family, all young people in the current study began by acknowledging their biological ties to parents and siblings first, but other factors also emerged from their accounts concerning the importance of practices of care to constructing meanings of family for young people living with a parent at the end of life.

4.2.1. Acknowledging biological ties

In describing their family, young people in the current study tended to name the biological relatives who were living with them first before 'moving outwards' to include biologically or geographically more distant relationships:

> *There's my Mum; there is my grandma, my granddad. Erm, my aunty down the street… there's my uncle, but like he lives down in the south. A good majority of my cousins actually would be in [country].*
>
> (James, 17)

> *Well at the moment it's just me, my Mum and my Dad that live there, but my sister used to live with us but went off to [city] a while back, although she's coming back now because of the family situation.*
>
> (Elliot, 18)

The acknowledgement of biological ties implies a conventional understanding of family as a nuclear household, but it is perhaps the sense of a shared genealogy and of belonging to a greater whole that gives meaning to family for young people, particularly when the integrity of family is threatened by life-limiting parental illness. For example, some young people responded to the invitation to tell me about their family by presenting a version of a family history; a story of their origins. Lauren and Jay began their 'family narratives' as follows:

> *OK, my Dad was originally from [country], he came over in 1980 and met my Mum and fell in love, you know, all that stuff. They divorced in 1994, the year after I was born. I've got an older brother who was*

born in 1989. We grew up in [city], but we moved here in 2000, and it was the best decision we ever made. (Lauren, 21)

My Mum and my Dad both were born in [country]. My Dad was married 3 times. My Mum's the third wife. Erm, they separated, they got divorced. After that my - before my Mum and my Dad got divorced my Dad used to beat my Mum quite a lot…so problems were happening from quite an early age for me. (Jay, 17)

The sense of family as the product of a collective story into which young people's lives are inexorably woven is sometimes apparent when young people distinguish family relationships from relationships with friends:

Friendships are a lot easier, are a lot easier to control in a way, cos you can easy just take them out of the equation, so to speak, but erm, I think family, it just gets a bit more complicated because it's kind of, you know, family's family really, so - you can't really escape that easily from them. (James, 17)

My family, I'll always have them - they're like my blood, and my Mum's illness has obviously like brought us closer and all - and my friends obviously mean a lot to me but my family will always be there...I'll have, like, my family when I need them to be there. (Ellie, 16)

For these young people, family is distinct from friendships in that young people are born into a family not of their choosing, and cannot easily separate their everyday selves from their experience of family. As these extracts demonstrate, this may be interpreted positively or negatively, but is a consequence of (biological) family being taken for granted as a 'given' in young people's lives. I will return to the juxtaposition of 'family' and 'friends' in young people's accounts in section 4.2.3. of this chapter. I now want to explore a second key theme in young people's descriptions of family present in the above quote from Ellie; that of 'closeness'.

4.2.2. Closeness and care

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

> *I see my aunty nearly every day. My Nana lives down the street and she's elderly and everything so my Dad does a lot for her but [aunty] technically does more cos she can really. I mean, my Dad cares for my Nana and my Mum.* (Luke, 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. 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 available to 'do family' through the practice of care.

The notion of closeness is also applied to describe the emotional bonds between family members, and in particular, bonds that have 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 have 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 closeness 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 seriously ill. 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 is often reflected in young people's accounts. Family members who are physically present in young people's everyday lives are presented as emotionally close, whilst those who are physically absent are 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 expect to rally round is indicative of their emotional distance. Conversely, the willingness of others to travel in order to be present and 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 caring are therefore inter-related concepts applied by young people to describe family and captured by the over-arching theme of 'being there'. The emphasis on family members being there (or not being there) encapsulates both the physical and emotional proximity associated with the meaning of family for young people with a parent at the end of life and engenders a sense of family closing ranks to consolidate its resources in the face of the existential challenge posed by parental illness.

As the quotes from Luke and Dan (p. 117) illustrate, the inability or refusal of relatives to be there is keenly felt by young people and is not only interpreted as a lack of care, but is also depicted as a moral breach of what might reasonably be expected from people defined as family. The lack of contact from friends is referred to less frequently, and in terms that suggest it is 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 suggests an understanding that friends may not always feel comfortable to be there for young people. However, the meaning of family appears to include a necessary sense of presence and a willingness to make oneself available to another who is in need. Young people do recognise the limitations imposed by geographical distance on the ability of family members to be there, but expect distant family members 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)

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 want 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 at the end of life reflect the finding from Finch & Mason's (1993) Family Obligations Project; '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 appears to underpin the accounts of young people living with a parent at the end of life, and takes on a particular, moral significance when there is limited evidence of this happening in their everyday lives.

Whilst it is likely that the absence of extended family members would not be as keenly felt by young people in less difficult circumstances, the absence of geographical and emotional proximity for young people in the current study was something they struggled to reconcile with their

meaning of family. I will continue to explore the significance of breaches to the moral expectation of family members *being there* later in this chapter. In the following section, I examine how young people constitute relationships as family-like on the basis of the presence of closeness and care.

4.2.3. 'Like family' relationships

The significance of closeness, care and being there in defining family for young people with a parent at the end of life is further illustrated by young people's references to friendships as 'like family' relationships:

> *It sounds daft but he is like family. He treats us like family and we treat him like family sort of thing, cos he cares.* (Luke, 18)

> *I've got a really big group of friends. They all know my Mum's problem. They all care for me, they all look after me. It's also the same for me to them as well. There are other people who have different problems, so yeah, it was kind of like a second family*. (Jay, 17)

It appears that, particularly in circumstances where they may be feeling let down by people whom they consider to be family, young people refer to family-like relationships with individuals who are offering the closeness and care associated with family. These 'like family' relationships may make up for a perceived deficit in family and offer young people the reassurance of belonging to a wider network of meaningful and inter-connected relationships. Ribbens McCarthy (2012: 75) describes the impact on one young person of being let down by her family in potent terms; 'a family that utterly fails to care for its members ceases to exist, which becomes a powerful expression of rejection'. For young people with a parent at the end of life, 'like family' relationships may be one way of ameliorating the existential impact of the threatened loss of family as a consequence of parental ill health. Young people's use of friends and like

family relationships as a resource for getting by when they have a parent at the end of life will be explored more fully in Chapter Six.

4.2.4. Being there and parental non-being

The significance of being there for young people in this study must be understood in the context of living with a parent who is not going to be there in the foreseeable future. Some young people chose to describe their family by making a direct reference to their parent's illness:

> *Well, my Mum's got bone cancer. I'm not sure every single place but I know she's got it in her hips, in her back, in her lung, in her skull, in her ribs. I think that's it. That's all I know of right now.*
>
> (Joe, 13)

> *I live with my Mum, my sister and my brother. Erm, if I speak like about my Mum's cancer and all of it; my Mum has cancer. She's not going to get any better.* (Ellie, 16)

For Joe and Ellie, thinking about family is subsumed by knowledge of their parent's illness, such that the meaning of family appears to be bounded by the experience of living with a parent at the end of life. In other words, some young people were unable to begin constructing a meaning of family beyond the frame of reference imposed by parental ill-health. Other accounts reveal how parental illness acts as a distorting lens and troubles the meaning of family for young people:

> Dan: *We're a very un-normal family.*
>
> Nicola: *In what sense?*
>
> Dan: *Just the way we cope with stuff and everything.*
>
> (Dan, 16)

> *I'm not really sure how to describe us. We're a bit weird I guess...it's strange to think about maybe how the dynamic of the family has changed.* (Elliot, 18)

> *I don't know whether it's because I grew up with my Mum so close and that, so obviously something's going to feel different isn't it? It just feels like, it does feel like there's a difference that I can feel, yes.*
>
> (Lauren, 21)

These terms ('un-normal', 'weird', 'different') appear to have been chosen to reflect the sense of otherness experienced by young people living with a parent at the end of life. This may be in comparison with members of their peer group, who are not living in these circumstances; but it appears that young people used this language to differentiate between everyday family life now and their experience in the past.

In doing so, young people avoided language which may be interpreted as either positive or negative and choose more equivocal terms. This may have been intended to protect their family from negative judgement and to sustain the impression of belonging to a 'proper' family, but it may also reflect the ambivalence and uncertainty felt by young people themselves. The everyday experience of ambiguity and change potentially distinguishes living with dying from living with death, and offers an insight into how the meanings of family and of parental ill health are each constituted, experienced and interpreted in the light of the other. The significance of uncertainty in the lives of young people in the current study will be explored in more detail later in this chapter (section 4.3.1.).

In this section, I have explored the meanings of family for young people with a parent at the end of life and considered how understandings of family shift in response to parental illness. Building on Mason and Tipper's (2008) empirical study of children's definitions of kinship, I suggest that young people work out the meaning of family relationships not only by acknowledging who their family members are, but also by assessing what they are prepared to do. Young people in difficult circumstances place more emphasis on family as a resource to draw on, and the extent to which family members can or cannot be relied on to be there is of practical, emotional and moral significance.

Parental illness both reinforces and undermines the core concept of being there in young people's understandings of family. Whilst the presence of family members appears to be more important to young people with a parent at the end of life, the absence of extended family in the everyday lives of young people poses a moral threat to their family narrative and troubles the sense of belonging to a 'proper' family. I will return to this latter point later in this chapter (section 4.4.1.).

Having considered *what* family means for young people with a parent at the end of life, I turn now to *how* young people 'do family' by exploring the everyday practices in and through which family is constituted and maintained.

4.3. DOING FAMILY

In the previous section, I considered the notion that change is a universal and unavoidable feature of everyday family lives (Mason and Tipper, 2008; Ribbens McCarthy et al., 2013) and summarised some of the changes that have been encountered in the family lives of young people in the current study. The ordinariness of change in young people's experiences of family supports Morgan's (1996, 2011) view that family is not a static set of relationships, but is constituted and re-constituted through everyday customs and practices. I draw upon Morgan's family practices approach in this section to explore how living with a parent at the end of life impacts upon the everyday routines and actions that comprise family from the perspective of young people. By drawing attention to what young people do during changing circumstances, and the 'little fragments of daily life' (Morgan, 1996: 189) that shape family for young people, I aim to increase understanding of young people's experiences of living with a parent at the end of life.

I begin by exploring how young people make sense of and respond to the changes in everyday family life engendered by parental illness. I consider the significance of uncertainty and ambivalence as themes in young people's accounts of everyday life, and examine the routines and practices

young people adopt when doing family in changing circumstances. Finally, I discuss how wider social narratives of family at the end of life influence the doing of family for young people, with particular reference to practices of communication in families when a parent is dying.

4.3.1. Encountering change

As previously stated, many of the young people in the current study had already encountered significant changes in their family lives prior to their parent's illness. In particular, five out of ten young people had faced loss in the form of parental separation, and five out of ten had experienced the death of a significant other such as a step-parent or a grandparent. Such events are rarely experienced as discrete and finite, but trigger changes that continue to ripple out through the lives of young people and their families. For example, after his parents separated, James and his Mum went to live with his grandparents. However, when his Mum's sister became ill, she also moved into their shared household, triggering further changes for James and his Mum:

> *So I think it was all decided that me and my Mum would move out to this house. I think it was just thought that having me and my Mum, my aunt, having us all there would just be a bit too much... My Mum asked for some time off work, like a long period, not only to adjust to the family situation, but to adjust to, you know, actually being in charge of the whole house just on her own, me and her.*
>
> (James, 17)

James and his Mum were no longer able to depend on the daily presence and support of his grandparents, and had to develop new routines and practices for doing family as they became more reliant on each other to maintain everyday family life. James's account illustrates how 'normal' family life for young people may be punctuated by loss, disruption and change. This raises the question of whether living with a parent at the end of life is best understood as an extraordinary change in a hitherto stable set of circumstances in young people's everyday lives, and the extent to

which parental illness troubles young people's everyday experiences of family life.

Whilst there is a need to be careful that the normalisation of difficult circumstances does not overlook harm (Ribbens McCarthy et al., 2103), young people can and do manage significant change including the loss of a parent (Jamieson and Highet, 2013). Research on young people who have been bereaved suggests that the death of a parent may be more or less troubling for young people depending on the complex interaction of a wide range of factors, such as the nature of the young person's relationship with their parent, the continuing availability of parental or parent-like care and access to other forms of support (Ribbens McCarthy, 2006: 139).

A factor that emerged in the current study, and may impact on the extent to which everyday family life is troubled when a young person has a parent at the end of life, is the length of time since the parent's initial diagnosis. Most of the young people in the current study had been living with parental illness for a significant part of their lives; for nine out of ten young people, their parent had been ill for between 6 and 12 years. Many were unable to recall much about their experience of everyday family life before their parent first became ill:

> *I can't remember a time when she hasn't been ill. Well, I struggle anyway. There was a little gap between the breast cancer and the bone cancer; there was a little gap of about three or four years but - she was still struggling with the tablets she was taking from the aftermath of the other lot of cancer and everything.* (Dan, 16)

> *I was not quite four at the time when she first - all I've known is her being ill and like, not being well and that. She's always had something wrong with her since I can remember. I don't think there was a time when she wasn't.* (Joe, 13)

The accounts of young people in this study therefore suggest that living with a parent at the end of life is a long-term project of assimilation and

endurance, rather than a short-term crisis in the life of a young person. This is not to say that moments of crisis are absent from young people's accounts; for example, some recalled a significant incident that first brought to their attention the seriousness of their parent's illness:

> *Whenever we've gone on holidays, well, me and my Dad this was part of the things that we've always done, we've gone and climbed a mountain, and me, him and my sister's boyfriend all went to climb one and as we were coming back, we realised my Dad had left his bag, but he was absolutely shattered. He was always the person who could handle climbing much better, but you know, obviously his body was getting a heck of a lot weaker, and he just, he asked me to go and get the bag.* (Elliot, 18)

Elliot's scenario illustrates how significant moments in a young person's experience of parental illness may be encountered in the context of the everyday routines that constitute family life. Elliot described how he became aware of his Dad's deteriorating health when the usual practice of taking part in a shared activity on a family holiday was disturbed. In this example, it is the juxtaposition between parental illness and the maintenance of 'normal' family routines and practices that foregrounds the significance of living with parental illness for a young person.

In other accounts, parental illness is assimilated into the routines and practices of family life such that young people retain a sense of everyday life continuing as normal:

> *I was aware that oh, she'd lost all her hair, she's gone bald, she's wearing a wig. That's at that time when I was about five, that was the only real change I was aware of...I was just like, 'Alright, what's for tea?' Really I wasn't, looking back on it now, you know I can see how it didn't really bother me because that was, in all fairness, that was the most big change there was.* (James, 17)

> *[Mum] didn't want it to change any of our lives. She wanted to carry on as normal, she wanted to go to work and she wanted to, you*

> *know, go round for a coffee with someone and go for a walk. She didn't want it to change her life and she didn't want it to change ours.* (Lauren, 20)

In these accounts, maintaining everyday family life acts as a counterbalance to alleviate the troubling uncertainty that may otherwise characterise living with a parent at the end of life. Previous research suggests that parents in particular strive to maintain a sense of 'normality' when a parent has a life-limiting illness in order to protect children from any negative consequences (Kennedy and Lloyd-Williams, 2009; Semple and McCance, 2010). The experiences of young people in the current study suggest that preserving the continuity of everyday routines and practices supports the assimilation of parental illness into a *new normal* for young people. Living with parental illness thus becomes part of the mundanity of everyday family life for young people until parental health deteriorates, and a further period of adjustment becomes necessary.

For young people in the current study, rather than representing an extraordinary crisis in their lives, living with a parent at the end of life is best characterised as a continuous process whereby significant moments are followed by periods of adjustment. This oscillating pattern of uncertainty and assimilation underpins the doing of family for young people and becomes part of the everyday; a new normal that characterises the experience of living with a parent at the end of life.

4.3.2. A new normal

Bowlby (2012) draws on Bourdieu's notion of habitus to argue for the importance of time to the practice of care in families. She suggests that past experiences of care are encompassed in taken for granted routines of behaviour that will be practiced in different temporal and spatial contexts. Similarly, I suggest that the practices involved in doing family for young people in the shifting context of living with a parent at the end of life are; 'rarely a matter of rational calculation and more a matter of routinised,

taken-for-granted attention to practicalities' (Morgan, 2011a: 2). The experience of uncertainty and change in the lives of young people with a parent at the end of life, often accumulated over many years, leads to the development of a new normal characterised by practices that constitute a routinised, taken for granted response to living in this particular set of difficult circumstances. Young people in the current study sometimes referred to the implementation of these practices using terms such as *keeping going* or *getting on with it*:

> *It just kept going as normal as I wanted. I figured that, if I kept going; that's one less thing for my Mum and Dad to be worrying about... I'm not ignoring it, I know it's there, I just see no point in letting things collapse and, there's not a lot really I can do about it in the first place*. (Matt, 20)

> *I don't think it's something that you talk about. You get on with it. I don't know, not in a harsh way, but in a - there's only so much talking about it can do isn't there?* (Lauren, 21)

> *It's weird but it's something that we've had to get used to cos there's nothing we can do about it so, it's just sort of there... I give as much support as I can give and I get on with it sort of thing.*
>
> (Luke, 18)

Young people's use of terms such as *keeping going* and *getting on with it* encapsulates the tension and ambiguity inherent in maintaining the balance between change and continuity and reconstituting a new normal in young people's everyday lives. Parental illness is acknowledged as an event that has had a tangible impact on everyday life, but over which young people have no control. However, rather than responding to parental illness as a life-changing crisis, these young people appear to have absorbed parental illness into their everyday lives; and in doing so, a number of family practices emerged as significant in helping to incorporate the uncertainty of living with parental illness into everyday family life.

Maintaining routines

Some young people responded to the uncertainty of living with a parent at the end of life by emphasising the everyday routines, largely determined by their attendance at school, college or work, that continue to shape their lives:

> *I get up around seven, sort myself out. Erm, my Mum gets up, she's got her tablets; she has to get up and get her tablets in the morning, so she's always up in the morning. Then I just go to school. I leave about half past eight in the morning, I like go to school; do all that, and then I don't get back until about half four. Monday to Friday I'm just at home really. I just go on the computer. Sometimes I'll go out with my friends*. (James, 17)

James's account illustrates how the experience of parental illness is incorporated into the mundanity of everyday life; his early morning contact with his Mum is explained as a consequence of her need to take her medication. In contrast, when parental illness cannot be easily assimilated into their everyday routines, this can be experienced as troubling for young people:

> *It's just one of them things when you just think about other people where they don't have to help their Mum. They can just go and play on their X-Box for hours on end or go and play football or something like that after school, but then when you realise that you can't cos you need to be home just in case something happens to Mum, or if your Dad goes out or something like that, - it's quite hard*.
>
> (Dan, 16)

Dan has had to accommodate the loss of freedom to do as he wishes after school into his new normal, and his account demonstrates that this process of adjustment can be difficult for young people. Jay has similarly had to give up the notion of having free time after school as consequence of his Mum's illness, but in his account he emphasised the importance of the daily routine of school attendance to his ability to get on with it:

> *It was kind of like my release time, if you know what I mean. If I'm at home I'm doing all the stuff, all the work; and it's kind of like if someone goes to work and then comes back home and then he doesn't need to worry about it, it's like it's his own time, but mine was separate from home. I went into school and that was my own time.* (Jay, 17)

Maintaining everyday routines can therefore be helpful to young people in that these practices provide some stability and continuity in the uncertain context of living with a parent at the end of life. Similarly, the next section outlines how young people emphasise the importance of maintaining certain activities; and in particular, practices that are identifiable as conferring a sense of family.

Maintaining specific practices

The accounts of some young people in the current study indicate how maintaining certain activities is important because they are activities that family members have participated in together, and therefore they continue to provide continuity to some family practices when others are disrupted:

> *Dad takes us along [to football]. He's always giving lifts and everything, and when we're at home on a Saturday Mum comes up and helps out with the tea and everything, so it's like a family thing.* (Dan, 16)

Being able to maintain football as a family activity is particularly important to Dan since his Mum's illness has meant that she is unable to travel, and therefore they can no longer go on holiday together as a family. Later on, he commented:

> *I think it's changed when you find out that like, friends and that have gone away and when they come back you see the smile on their face and you're thinking, 'Why can't we go away and have fun for once?'* (Dan, 16)

Being able to enjoy shared activities appears to be a significant marker of family for young people. Lauren recalled:

> *Mum had a barbecue in July, August. Just like a family barbecue, and they all came up for that, you know. A couple of beers and some burgers and sitting in the sun, it was just really nice. Lots of good pictures.* (Lauren, 21)

Lauren's reference to photographs taken at the barbecue indicates the importance of being able to display family and point to the material evidence of 'doing family things' (Finch, 2007: 67), not only in the present but also into the future. I suggest that implicit in Lauren's account is the sense that these photographs not only demonstrate her family relationships are positive and effective, but also imply that they will endure into the future beyond her Mum's death through the material forms of family images. In this context, family photographs may serve to sustain memories of a deceased family member and also confer on Lauren a sense of the continuity of family relationships beyond the anticipated loss of her Mum.

The maintenance of certain practices which confer a sense of doing family is therefore important in enabling young people to establish a new normal when they have a parent at the end of life. However, as parental illness progresses, young people and their parents may also develop new family practices to accommodate the everyday routines and activities of living with a life-limiting illness.

Finding new ways of doing family

Lauren's account draws attention to the significance of time and space in configuring everyday family lives (Daly, 2003; McKie et al., 2002). When a parent is at the end of life, the spaces for doing family become more constrained; for example, family holidays may no longer be possible (as Dan's account indicates). Sometimes, young people make the best use of available opportunities and find alternative ways of doing family that take

into consideration their parent's illness and the routines and practices through which palliative and end of life care is delivered.

For example, Lauren described how accompanying her Mum to hospital for treatment functioned as a social outing, through which she was able to maintain her close relationship with her Mum:

> *I know this sounds very odd, but we actually had really nice days. We'd, you know, check in at the hospital, have a nice walk if it was sunny, have some lunch. It didn't feel like a bad day. Then we had to go every week, and again it was just a nice day, eating ice cream or lunch or something, so it wasn't something that I dreaded and I don't think it was something she dreaded either*. (Lauren, 21)

Elliot explained how his Dad no longer feels able to go out for a drink with his Mum:

> *They kept up going to the pub at least once or twice a week for a while, but I think it's kind of stopped a bit from about two months ago or whatever. It's become a bit more convenient for them to just have a bottle of wine at home and spend time with each other, and I try and give them time to do that with each other every so often*. (Elliot, 18)

Elliot participates in ensuring that this activity, which contributes to his understanding of 'normal' family life, continues in a new form by giving his parents space to share time with each other at home. In general, opportunities to engage in the routines and practices that shape everyday family life tend to become more limited to the family home as parental illness progresses. Young people primarily engage in family-constituting activities in the home, whilst time away from home is maintained for being with friends or for working towards future aspirations. These themes will be explored in more detail in Chapter Five, where I discuss practices of care in families with a parent at the end of life, and in Chapter Six, which focuses on young people's use of resources beyond the family.

In this section I have argued that the experience of living with a parent at the end of life is characterised by uncertainty and change that has often taken place over a period of years, sometimes for most of a young person's life. Accommodating cycles of disruption and adaptation becomes the new normal in terms of doing family for young people in this context. Certain practices have been identified as helpful in enabling young people to configure a new normal in and through their everyday lives. In the following section, I consider how wider social narratives of a good death and of family care at the end of life may serve to both support and challenge the maintenance of family for young people with a parent at the end of life.

4.3.3. A new normal and the narrative of a good death

In the literature review (Chapter Two), I discussed the centrality of the idealised notion of a 'good death' to UK policy and practice in end of life care. The influence of this ideal on young people's experiences of living with a parent at the end of life can be detected in Lauren's account of her Mum's deliberations with regard to place of death:

> *She said that she wanted to die at home when she knew that she was going to die. She always said at home, but I don't think she quite realised what it would be like, how hard it would be. Her needs are changing I think, and so is her mind, but obviously there's not that many hospices around here.* (Lauren, 21)

Lauren has provided a substantial amount of care for her Mum during her illness (this will be examined in more detail in Chapter Five), in part to fulfil her Mum's stated wish to die at home. Up until recently, Lauren's actions in making continuous adjustments in her own life to accommodate her Mum's escalating need for care have been congruent with the narrative of a good death; and providing care for her Mum has become the new normal for Lauren, something she simply gets on with (Lauren, p. 128). However, as her Mum nears the end of life, Lauren reflected on how

her Mum's wishes have changed, and the new moment of crisis this has precipitated:

Lauren: *Like I said, for me, I don't want her to go into hospice because I always thought that wasn't what she wanted and she's doing it because she feels like she's a burden, but she isn't.*

Nicola: *Has your Mum talked to you about her decision to go into the hospice?*

Lauren: *Yes, she has, yes, and I wasn't very happy about it. I'm very sad about it, because like I said, I thought it wasn't what she wanted, but it's just that everything has changed. We're not the same people that we were when we made the decision the year before, six months before or whatever. I think it would be fine at home if someone came to my house and said, 'Look, this is what to expect. This is what you should do, and this is what will happen'.*

Lauren appeared troubled by the thought that going into a hospice is not her Mum's 'true' preference, but is motivated by her concern for Lauren. The change in her Mum's stated preference with regard to place of death has disrupted the everyday doing of family and the practices of care Lauren has evolved to support her Mum at home. Whilst she recognised that the process of dying has inevitably triggered change for her Mum and herself, Lauren is disturbed by a sense that she may be letting her Mum down by ceasing to care for her at home.

This extract illustrates the potency of the narrative of a good death as one that takes place at home accompanied by family members (Pollock, 2015). Lauren's reconstitution of a new normal in everyday family life has been bounded by this prerogative, and the possibility that she may not be able to enact it challenges the doing of family when a parent is at the end of life and reintroduces a troubling sense of uncertainty for Lauren.

The uncertainty that this new period of adjustment generates is exacerbated for Lauren by the essential unknowability of death itself. Lauren is troubled by her lack of awareness of the process of dying and of what will happen at the very end of her Mum's life. This represents one way in which the experience of living with a parent at the end of life differs from that of young people who have been bereaved. The uncertainty of dying and death casts a shadow over young people's experiences such that everyday life is constituted in the context of a fundamental sense of ambiguity. Elliot reflected on his feelings about his Dad's dying and death as follows:

> *I don't know how I'm going to deal with it because I don't know how it will feel, but I'm not saying I don't know how I'll deal with it in terms of will I deal with it, it's more I don't know what that situation is going to be like at all. I don't know if it will feel similar and different or completely different at all*. (Elliot, 18)

Rather than responding to the discrete event of a death, young people in the current study are dealing with a continuous process of indeterminable change. I suggest that this shifting landscape of uncertainty and the corresponding process of adjustment constitute a new normal for young people, which is enacted and maintained through the everyday doing of family. Wider social narratives of a good death affect how families respond to changing circumstances when a parent is at the end of life and influence the practices that are incorporated by young people into a new normal.

In the following section, I consider the example of family practices of communication, or how family members 'do talking', as a particular illustration of the way in which discourses drawn from end of life care policy and practice are incorporated into the activities of daily life and shape the everyday experience of family for young people living with a parent at the end of life.

4.3.4. Family communication practices

In the literature review (Chapter Two), I discussed how policy and practice in end of life care promotes the importance of open communication with and between family members when someone has a life-limiting illness (Department of Health, 2008; NPELCP, 2015). Practices of communication between family members are therefore regarded as significant in enabling young people to navigate the experience of living with a parent at the end of life. In this section, I consider how the way in which family members 'do talking' in the current study sheds light on doing family when a parent is at the end of life. In particular, I bring in some parental voices to illustrate how the multiple perspectives approach applied in the current study highlighted differences between young people's and parents' accounts of communication between family members.

Some parents in the current study presented communication with young people regarding parental illness as a parental duty; a form of moral obligation:

> *It wasn't easy telling them, but I wouldn't have wanted anybody else to tell them, and as for everything else, we tell them everything. We don't keep anything from them...If I'd kept them out of it, they'd never forgive me, so we've always told them. I wouldn't have it any other way; I couldn't not tell them.* (Shelley)

For Kathleen, her son's age at the time of her initial diagnosis influenced her decision not to tell him about her illness, even though she was aware that it was something she *should* do:

> *Now, I know literature says you must tell your children. Be up front with your children no matter what age about your condition, but I've found, for me, when I was diagnosed he was between 3 and 5, I forget really...I feel that nothing was ever spoke about in front of him on reflection, but he was in the house and I feel he picked things up; which, was that good or bad?* (Kathleen)

Kathleen's account illustrates the moral dilemma an emphasis on open communication presents for parents between keeping children informed and protecting them from potential distress. Her rhetorical question indicates the significance of communication as a moral practice in families with a parent at the end of life, through which parents try to work out the proper thing to do. In their descriptions of doing talking, some parents appeared to be demonstrating that they are 'good' parents in spite of the debilitating effects of parental illness. I return to the notion of moral tales in everyday accounts of living with a parent at the end of life from the perspective of young people later in this chapter. Here, the intention is to provide a backdrop for young people's experiences of communication within the family and to illustrate how this context is informed by the discourse of open communication as the 'proper thing to do' according to end of life care policy.

Parental references to an open style of communication between family members were not always supported by young people's accounts. For example, although Joe's parents described communicating openly with their children, Joe's account presented a more circumspect approach to doing talking:

> *We don't talk about it as a family, no, not really...[Mum and Dad] said that they'd tell us if like, anything changed, and like if - things got worse or they got better they said they'd tell us.* (Joe, 13)

Furthermore, there may be a difference between the *knowledge* given by a parent to a young person and the young person's *acknowledgement* of the information; or the way in which a young person absorbs and incorporates the meaning of the information into their everyday life. Some young people reported that they did not always acknowledge what parents had said to them:

> *You can be told about things but you don't realise exactly the implications of that until you see them. It's only seeing my Mum in*

the bed, wired up and drips everywhere and everything like that. That got me worried a bit. (Matt, 20)

They did tell me and I didn't - I think I vaguely remember the conversation when my Mum was saying, 'This could be bad'. I remember it not affecting me that much cos I thought, 'Ok, it could be bad, but bad has; there's a lot of variation within the definition of bad'. (Elliot, 18)

These comments reflect research in end of life care which indicates that people who are dying may move between states of denial and acceptance of their prognosis in the process of getting on with their everyday lives (Copp and Field, 2002). Similarly, some people may resist attempts to instigate a state of open awareness in which the certainty of death in the foreseeable future is acknowledged (Almack et al., 2012; Richards et al., 2013). The accounts of young people in the current study point towards a similar process of young people maintaining a sense of ambivalence through their communication with family members when a parent is dying. This raises questions about the extent to which young people want to know about their parent's illness and prognosis, and whether such knowledge is always experienced as beneficial.

Some young people acknowledged the importance of communication and regarded the sharing of information about their parent's illness as a product of the close relationships that exist between family members:

I can always just go up to my family and talk to them about it, and even if it's something that's so deeply involves them it's not a problem. They're - erm, I'm not really sure how to word that, but that's in this situation one of the things that's been most important to me about my family. (Elliot, 18)

We just talk openly about everything that's going off...I think when my Mum got ill the first time things quietened off. I was only young but I noticed little things like that, but this time they've been really

open this time cos they realise they couldn't hide it like they did last time. With how old we are, we'd notice if something was going off.

(Dan, 16)

Some young people's accounts challenged the positioning of young people as passive recipients of information. Instead, young people presented themselves as active agents seeking out information on their own terms and shaping practices of communication in their everyday family lives:

This time I ask, obviously I ask a lot more questions. They might disagree but I try to do whatever I can to help. I keep making myself seem as interested as possible. I always want to know when there's, if there's a problem or - something's happened. I'd want to know sort of thing; so I keep myself as close to the, close to it as possible.

(Luke, 18)

I would usually go to my sister, because she has this card thing that she can go to the hospital or something and she can, like ask them what's up with my Mum and they can tell her and then; sometimes my sister and my Mum don't want to tell me but also, I want to know, so they tell me. (Ellie, 16)

These comments suggest that open awareness of parental illness in the context of a young person's family is valued. However, it is notable that open communication is not invariably regarded as positive; some young people were careful to calibrate the amount of information they received, and to determine when they had as much information as they wanted:

I knew enough for me, well - I don't necessarily ask but you know, she always just lets me know. She just tells me; she lets me know when she's going for a meeting and stuff and, that's alright, you know. I don't - I don't really push for any information. I feel that I could ask but - I just don't really. (James, 17)

I don't want to understand like everything to do with it. It's not something I really wanted to know. I don't really want to know what the - like what cells or whatever it is that's killing my Mum. It's not

exactly as if I'd want to sit there and say, 'Oh right, now I know. I know what's killing my Mum'. (Joe, 13)

Some young people choose not to ask questions, or avoid pursuing conversations about aspects of parental illness they prefer not to discuss. The accounts of young people in the current study therefore suggest that rather than endorsing the practice of open communication between family members, young people prefer to exercise some control over their knowledge of parental illness and prognosis. Having some choice over how much information they receive and when may facilitate the ability to move in and out of a state of open awareness and enable young people to better accommodate the experience of parental illness in their everyday lives.

Contrary to established policy and practice in end of life care, the current study indicates that open communication is not necessarily regarded as beneficial by young people with a parent at the end of life. Instead, young people appear to shift their position along a dimension of *talking/not talking* in order to facilitate getting on with their lives. Young people exercise agency in making decisions about what to talk about and when, and in shaping practices of communication between family members. In doing so, young people demonstrate their active involvement in the fine-tuning of family practices in response to the difficult circumstances of living with a parent at the end of life.

This examination of practices of communication in everyday family life sheds light on how the discourses contained within end of life care policy and practice can affect young people's experiences of living with a parent at the end of life. For parents in the study, keeping young people informed was one way in which they sought to fulfil their responsibilities as parents by acting in accordance with policy recommendations. However, young people presented a more nuanced interpretation of the benefits of open communication, and advocated a more *careful* approach. I will return to

the ways in which young people seek to communicate *with care* when they have a parent at the end of life in Chapter Five.

In this section, I have alluded to ways in which communication serves as a moral practice; an enactment of the moral deliberations that underpin the everyday doing of family and are informed by broader cultural narratives concerning how family members *should* behave in this context. In the following section, I expand on this theme and explore some of the moral tales of doing family that emerged in young people's accounts of everyday family life.

4.4. MORAL TALES OF FAMILY AT THE END OF LIFE

Integral to Morgan's concept of family practices, he argues that 'morality has rarely been far away from family living' (2011: 127). In particular, he suggests that the core principles of fairness, obligation and reciprocity have their origins in relationships between family members, and that it is though the everyday practices of decision-making in families that we learn how to work out the proper thing to do. Empirical evidence from Finch and Mason's (1993) Family Obligations study supports the view that in choosing how to enact relationships with family members, adults do not draw on abstract moral principles, but work out an ethical practice in and through the routines and actions that constitute everyday family life.

The significance of moral tales in the study of family lives is addressed in a study by Ribbens McCarthy et al. (2000) of family practices following divorce, separation or re-partnering. Ribbens McCarthy et al. (2000) are concerned with how adults construct a narrative of family in order to position themselves as morally competent and as doing the right thing in response to changing family circumstances. In this section, I examine the moral tales of family told by young people in the changing circumstances of living with a parent at the end of life and explore the wider social narratives that form the context in which moral tales of family at the end of life are told.

Morgan (2011) refers to the significance of *moralising discourses*; 'public discourses about right and wrong and how these might apply to family living' (2011: 129), and the impact such discourses have on everyday family lives. The family has often been scrutinised as a site of political and social concern; for example, Ribbens McCarthy et al. (2013) explore how moralising discourses around the troubles all families experience tend to target those who are most economically disadvantaged and obfuscate the boundaries between the 'troubling' and the 'normal' in everyday family lives.

The blurring of boundaries between what may be regarded as routine occurrences and events that carry the potential for harm is particularly salient to an exploration of the experiences of young people with a parent at the end of life. Jamieson and Highet (2013) discuss how the prevailing moralising discourse of 'tragic loss', together with the associated status of victimhood conferred on young people when a parent has died, left little room for manoeuvre for young people who wanted to get on with their lives outside of a framework of continuing trouble. These moralising discourses may equally affect young people *getting on with it* when they have a parent at the end of life.

Furthermore, Jamieson and Highet (2013) cite the experience of a young woman whose mother worked to create a shared sense of a good death while her father was dying as an example of how families can contain or minimise the sense of loss resulting from the death of a parent. However, this analysis overlooks the point that a good death is in itself a moralising discourse, with the embedded implication that there is a proper way to do death. For individuals and families who are unable or unwilling to meet the requirements of a good death, this discourse may further trouble, rather than contain the experience of loss.

The notion of a good death may therefore be troubling, and its impact on the experience of young people with a parent at the end of life warrants further attention. In the following section, I explore the moral tales of

family that are woven into young people's accounts of living with a parent at the end of life, and consider how the moralising discourse of a good death informs young people's narratives of living with dying.

4.4.1. Tales of being there

Earlier in this chapter I suggested that the absence of people who are regarded as family from the everyday lives of young people when a parent is at the end of life represented a breach of young people's expectations of family in this context. The heightened awareness of what family members *should* be doing in terms of *being there* is one of the moral tales implicit in young people's accounts, and is underpinned by the moralising discourse of accompanied dying as an essential component of a good death. The notion that family members should rally round to offer support and comfort is not always realised in young people's everyday lives, and 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 are doing the *wrong* thing by not visiting, even though they have the resources to act in the proper manner. The absence of legitimate excuses sometimes leads 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 morally 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 moral tale leads him to conclude that his uncle is a 'bad family member', and demonstrates the struggle some young people experienced in stitching together a narrative of a proper family. In Ellie's quote above, she is constructing a moral tale by emphasising that her Gran is available to do the right thing even though her Dad is not. This resonates with Wilson et al.'s (2012) study 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 the obligation to 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 moralising discourse of achieving a good death through being there for family at the end of life.

4.4.2. Competing tales of caring for children and caring for the dying

The dilemma of constructing a moral tale of family when a parent is at the end of life may be further exacerbated by the increased vulnerability of a parent who is approaching 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 (Emanuel et al., 2007; 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 perceived as warranting a focus on the

practical, relational and personal tasks relevant to the individual process of dying (Emanuel et al., 2007).

Ribbens McCarthy et al.'s (2000) study of families facing change suggests that in responding to family troubles there is a 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. I suggest that when a parent is at the end of life, the actions of young people and family members are 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 was shifting, and indicated that the everyday doing of family had been troubled by this change in priorities. For example, although parents interviewed for the study often spoke of being there for their children, young people reported that their parents were not always able to be 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)

The multiple perspectives approach therefore revealed that young people do not wholly endorse their parents' moral tales of being there for them; and that in deliberating on these unarticulated changes in family

practices, young people are actively working out new ways of doing family when a parent is at the end of life. Lauren's account 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 is reflecting on her awareness that her Mum is no longer able to put her needs first. Lauren's response has been to reverse the direction of moral obligation in her everyday family life by being there for her Mum:

> *Well I go to all of her appointments with her so she can't really hide much from me...and with the chemos and all that I was always there, so she couldn't not tell me things because the doctor was there telling me things... 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)

One way for young people to sustain a moral narrative of family when their parent is dying is therefore to fulfil the expectation associated with the good death discourse by caring for their parent until the end. I will continue to explore these competing moral imperatives and the shifting moral terrain in which young people's involvement in family care takes place in Chapter Five.

The accounts of young people in this study indicate that the inter-weaving of moralising discourses concerning being there for family members and the provision of a good death in young people's everyday lives is complex and sometimes challenging. In this section, as an example of the unpicking

of this moral tapestry, I 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 moral narrative of a good death. Conversely, being able to cite instances when family members have been there, or where young people have 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 when a parent is at the end of life.

For young people who are living with parental illness, the weaving of a moral tale appears 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. I 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 when they are living in these difficult circumstances.

4.5. CONCLUSION

In this chapter, I have explored how living with a parent at the end of life troubles the meaning, practice and moral significance of family for young people. I have considered how parental illness intersects with everyday family life, and the extent to which young people's experiences of one can inform and make sense of the other. Young people's narratives suggest that living with a parent at the end of life is a lens through which young people interpret and understand their experience of family, but that it is also in and through their everyday family lives that young people make sense of living with parental illness.

In young people's accounts of living with a parent at the end of life, family is characterised by notions of presence, closeness and care; meanings that are informed by everyday experiences of absence, change and loss. Many young people were doubly troubled by living with dying on the one hand, and by belonging to a family that has failed to meet the expectation of

family members being there on the other. Whilst young people's prior experience of change supports the view that family is a fluid construct and capable of adapting, the defining familial characteristics of cohesion and mutual support appear to be particularly significant for young people when they are living in these circumstances.

I have applied Morgan's family practices approach to explore ways in which young people make sense of and respond to parental illness through the mundane routines and actions that constitute everyday family life. I have argued that living with a parent at the end of life is a long-term project of assimilation and endurance for young people, in which short-term crises associated with changes in parental health over the trajectory of an illness are followed by periods of re-adjustment and adaptation. This oscillating cycle of change and uncertainty becomes a *new normal* for young people, and often extends over a period of many years. Certain practices have been identified that support young people in *keeping going* or *getting on with it,* and take into account the routines and practices that shape the delivery of palliative and end of life care.

I have described how the everyday doing of family at the end of life is informed by wider social narratives and discourses drawn from end of life care policy and practice; for example, the identification of an open style of family communication as the proper way to *do talking* when a parent is at the end of life. The multiple perspectives analysis of family communication practices I have presented has highlighted differences between young people's and parents' accounts of communication between family members and drawn attention to the importance of recognising young people's agency in determining the flow of information between family members. For some young people, being able to exercise choice and control over when and how to acknowledge facets of their parent's illness appeared to be a factor in enabling them to accommodate the experience of parental illness in their everyday lives.

Furthermore, I have considered how the moralising discourse of a good death as one that takes place at home accompanied by family members influences young people's responses to the changing circumstances of living with a parent at the end of life, and the practices young people incorporate into a new normal. I have argued that the notion of a good death may further trouble the everyday experience of living with dying for young people, and that the good death discourse encompasses a new moral imperative for family members to put the needs of the dying person first. Shifting the moral focus of family away from meeting the needs of children inevitably impacts on the everyday experiences of young people and the extent to which they can depend on parents or other family members for the support they may have received in the past.

Nevertheless, Ribbens McCarthy et al. (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 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, and points 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 relational experiences of dying and on enhancing the everyday experiences of all family members when someone has a life-limiting illness.

Further research that takes a more nuanced approach to the meaning, practice and moral significance of family in the everyday lives of people who are at the end of life and those who are important to them may help to establish what the notion of a good dying might encompass, and open up to scrutiny dying and death as a relational experience, as opposed to an individual rite of passage.

The current study affirms family as a site of major significance for all those involved in experiencing the end of a life. In the following chapter, I turn to a concept that is arguably at the core of family, and pivotal to an understanding of everyday family life when a parent is at the end of life; that of care.

CHAPTER FIVE: CARE

5.1. INTRODUCTION

In this chapter, I consider the meaning, practice and moral significance of care in the everyday lives of young people with a parent at the end of life. Notions of care were closely woven into young people's accounts, such that if family constitutes the warp of young people's everyday experiences, the weft may be characterised in terms of practices of care. Care as a process of recognising and responding to the needs of others is central to our understanding of family lives. Brannen and Heptinsatall (2003) write, 'The engine of family life is 'care' – care defined in terms of the practice of caring and care as being cared for' (2003: 183). For young people in particular, being able to rely on the actions of others to meet their needs is vital for their survival, growth and well-being.

The research literature on young carers indicates that young people are often involved in caring for family members who have a disability or a long-term condition (Hounsell, 2013). It is reasonable to assume that some young people living with a parent at the end of life will also take on caring responsibilities for their parent; providing practical, emotional and even intimate care. As I have discussed, the experience of living with a parent who has a life-limiting illness is not wholly uncommon in young people's lives, and care for a dying parent may be ongoing over many years. However, this has not been reflected in the literature on family care at the end of life to date, where there has been scant attention to young people's experiences and enactment of care in circumstances which may be seen as troubling. It seems clear that the policy drive towards increasing the number of deaths that take place at home has implications for all family members, including young people. The experiences of young people in providing end of life care and the effects of the shifting dynamics of care in families when a parent is dying therefore merits closer scrutiny.

Research on the family lives of young people living in difficult circumstances has explored the on-going significance of idealised notions of the normative family through an interrogation of the shifting dynamics of care in the context of parental substance misuse (Backett-Milburn et al., 2008; Wilson et al., 2012). In their accounts of living in difficult circumstances, Wilson et al. (2012) describe how young people's references to practices of care underline their efforts to renegotiate and redefine the boundaries of family.

Philip (2013) has described the analytical potential of care as a concept that has particular value for shedding light on 'the interplay between practical, ethical and emotional dimensions of family relationships' (2013: 1). She argues that it is the potential for care to reveal the moral significance of relationships between family members that is particularly useful to developing an understanding of family lives. In this chapter, I apply Philip's analysis of care to explore the moral dimension of young people's family lives when they have a parent at the end of life, and to examine young people's actions as moral agents in constituting everyday family life in the context of living with dying.

The everyday experiences of care in the accounts of young people in the current study may therefore help to illuminate our understanding of how family lives are shaped by and for young people when they are living with a parent at the end of life. I begin the chapter by examining how young people talk about care in their accounts of family life. I outline the concepts young people draw on in describing care in the context of the family, and consider how these conceptual tools are applied to shape and reflect the meaning of family for young people when a parent is dying.

5.2. DESCRIBING CARE

Young people's accounts reflected broader understandings of care as both an emotional practice of *caring about* and a physical practice of *caring for* others (Ungerson, 1983; Tronto, 1993). However, before I describe these manifestations of care in the accounts of young people with a parent at

the end of life, I draw attention to the iteration of care as being responsible for another. This appears to be particularly pertinent for young people when the dynamics of care between family members are troubled by the experience of living in difficult circumstances.

5.2.1. Care as being responsible for another

Young people's narratives of everyday family life often included references to family members who 'take care of' them; particularly when their parent who is ill is unable to do so. For example, Elliot explained:

> *When my Dad went into hospital, my sister wanted to come down cos it was becoming slightly apparent that he might not just be in there for a couple of days, but yeah; they came down and then that's who was there 'to take care of me', quote unquote.* (Elliot, 18)

Young people appear concerned to identify who is responsible for their well-being in the absence of their parent. To *take care of* in this context may include the provision of practical care, but it also denotes the acceptance of a responsibility to keep a lookout for the young person. Lauren illustrates this interpretation of taking care through her description of the loss she feels as her Mum approaches the end of life:

> *It's not that you have to fend for yourself, it's the wrong expression, but it's, erm - I don't know the right expression. You're not on your own, cos you're not on your own, but it's like my Mum always had my back. That's how I'd describe it, and now people still have my back, but it's not the same*. (Lauren, 21)

In applying the notion of taking care as being responsible for another's well-being, young people reflect the normative assumption that parents are responsible for their children and that everyday family life is configured in a way that meets this expectation. Thus, when a parent is unable to fulfil this role due to illness, young people seek to identify someone else who can be responsible for them instead. For some young people, the sense that no-one can take care of them as effectively as their

parent can be experienced as troubling. One way in which young people respond is by emphasising ways in which their ill parent continues to care for them in spite of their deteriorating health:

> *She's not exactly very good in the morning, but that's only up until she takes her tablets and after she takes her tablets she can do all the things. Like, she can do all the washing and sit there shouting at us all, stuff like that.* (Joe, 13)

> *I mean even with everything going on with her, she's always interested in everything that's going on with me… She still cares for all of us.* (Luke, 18)

These young people seek to reassure themselves that their parent is continuing to take responsibility for their well-being, and in doing so, they present their parent in a moral light as fulfilling their parental duty. This reflects the study by Wilson et al. (2012), in which some young people tried to shield their parent from potential criticism by emphasising examples of 'good' parenting practices. Being able to demonstrate that their parent *cares about* them is important for young people, even if they are not able to *care for* them effectively at times (Backett-Milburn et al., 2008).

In some accounts, young people describe how the responsibility to take care of family members has shifted in order to convey the impact of parental illness on their everyday family life:

> Matt: *Before Mum, yeah, had got the cancer it was quite different. For one, we didn't even see even half as much of my Dad as what we do now, not even half cos he'd be always at work or he'd be in bed before his night shift so, it would be a rarity that you'd see him, probably for a few hours on a night if you were lucky and that. I'd say Mum was always the one main parent looking after us.*
>
> Nicola: *That changed, did it?*

Matt: *Yeah, more or less immediately. It immediately changed from that cos Dad was never working. Within a few weeks my Mum had had her operation, my Dad was doing all the looking after us and that*. (Matt, 20)

For Matt, his Mum's diagnosis triggered a change in roles and responsibilities between his parents and transformed the everyday routines that constitute family life. This illustrates how the diagnosis of a life-limiting illness has far-reaching effects that impact beyond the ill person to disrupt the lives of others with whom they have a significant relationship, including young people. Young people's accounts therefore highlight the significance of relational identities at the end of life, not only in terms of how family mediates end of life care (Broom and Kirby, 2013) but also the way in which family is mediated by the parent's need for care.

For other young people, parental illness leads to an awareness that they may have to take on more responsibility, either for themselves or for their parent:

I'd say I've just become a lot more cautious, you know, offering - I just offer my help a bit more and just, you know, try and take a more active role and start cooking for myself and stuff. I think just trying to probably take up a more adult responsibility. (James, 17)

James's reference to 'adult responsibility' underscores the assumption that taking care of his well-being is a role he associates with adulthood, not with his status as a young person. The gradual adoption of responsibility for the self is generally understood as a normative function of adolescence, albeit one which may be accelerated or derailed by living with a parent at the end of life (Philips and Lewis, 2015). In contrast, the notion of having to be responsible for a parent is non-normative for young people and appears to be more troubling, as the following extract suggests. Here, Luke is describing an incident when his Mum dropped her purse and asked him to pick it up for her:

Well by the time I'd walked round, she was on her hands and knees trying to grab it, so when I got round and grabbed it I sort of went, 'I told you I was walking round to get it'. I was quite harsh with what I said, and I said 'You're just being stupid doing that' and she had a go at me for it, obviously because it's not nice having your kids talk to you like that but, I'm not going to sit there and act like it's alright when she's doing something like that. If I feel it's stupid, I said I'd tell her…Later we were sat talking and she told me how she was, she hates how everyone gets on her back sort of thing, and obviously you're always going to see it from her side but, I just tried to give her a bit of an insight into how it feels for us, cos obviously she sees it as everyone getting on her back but we see it as her doing something daft, and if we didn't say anything she'd just do it over and over again and eventually she's going to catch herself out.

(Luke, 18)

Luke's inference is that he has to take on more responsibility for his Mum's well-being since she is perceived as no longer able to act in her own interests or those of her family; this places some strain on their relationship and occasionally leads to conflict. Whilst Luke appears to want to protect his Mum from harm, writers such as Tronto (1993) and Barnes (2012) have written about the difficulty of conflating the notion of protection (whereby individuals in receipt of care may be denied the opportunity to express their needs) with the concept of care. Barnes (2012: 7) argues 'there are certainly times when what is called care becomes something else', raising the question of whether the care provided by young people with a parent at the end of life can always be seen as 'good' care, or even as care at all. This will be addressed in more detail later on in the chapter (section 5.4.), where I explore the moral tales of care in young people's accounts of living with a parent at the end of life.

A final example of the meaning of taking care as being responsible for another draws attention to the issue of what happens to a young person when their parent dies if there are no other adults with parental

responsibility for them. Jess lives with her Mum, who is ill, and her younger siblings:

> Jess: *I've always learned how to look after myself and [my siblings]…Well, if anything happens to my Mum I'll be watching [them].*
>
> Nicola: *Has anyone spoken to you about it? About what might happen?*
>
> Jess: *No, cos I know I'll be getting them*.
>
> Nicola: *Has anyone asked you that?*
>
> Jess: *No I've told my Mum that. No-one else is getting them; I'm getting them. I don't see the point in separating us.*
>
> (Jess, 17)

Jess expressed her wish to be given parental responsibility for her siblings in the event of her Mum's death so that they can continue to live together. This indicates that some young people may be prepared to take on a significant responsibility for others in order to maintain family in difficult circumstances. Some researchers have disputed the idea of 'parentification', or the process by which a young person is expected to fulfil a parental role, as an accurate description of young people's involvement in family care (O'Dell et al., 2010; Rose and Cohen, 2010). However, Jess's account suggests that there may be specific circumstances in which young people do seek legal and social recognition of their parental role in relation to other family members.

One manifestation of care in young people's narratives of living with a parent at the end of life is therefore that of being responsible for the well-being of another. Young people appear concerned to demonstrate that they belong to a family in which the normative practice of adults taking care of children is adhered to in spite of parental illness. When the capacity of parents to take care has been troubled by parental illness, young people seek to provide a legitimate account of changes in the

practice of taking care that continues to present their family and themselves in a moral light.

I will return to examine the moral significance of care in young people's accounts of everyday family life later in this chapter. In the following section I consider the iteration of care as a practice in young people's accounts and explore how young people describe *doing care* when they have a parent at the end of life.

5.2.2. Care as a practice

Young people's accounts of living with a parent at the end of life are underscored by references to care as both a physical and an emotional practice. Bowlby (2012) makes the point that it is possible for the emotional practice of *caring about* to take place without the physical activity of *caring for,* and vice versa. However, for young people in this study, emotional and physical practices of care were seldom presented as discrete and separate activities, but were closely interwoven throughout their narratives of everyday family life.

The following extracts illustrate how physical and emotional practices of care are mutually constituted for young people when they have a parent at the end of life:

> *I think one of the biggest things is pushing her in the wheelchair. It's just something that confuses you. Like, am I really pushing my Mum in a wheelchair? You thought you'd do that when she was about eighty-odd, when she's getting old, not when she's just turned forty, so it's one of them things that just messes with your head*.
>
> (Dan, 16)

Ellie: *It's like emotional because my Mum's always in pain and she tells me she's in pain and I can't do anything*.

Nicola: *So what do you do when she says that?*

Ellie: *Nothing, cos like, I go to her 'What can I do?' She goes, 'You can't do anything, no-one can', so she usually just takes like*

her medication or something for the pain but it doesn't help.

(Ellie, 16)

For Dan, the act of pushing his Mum in a wheelchair triggers an emotional response to her need for assistance; whilst Ellie's emotional reaction to seeing her Mum in pain prompts her to ask what she can do to help. Caring about a parent (attending to need) may therefore precede or be prompted by care-giving (acting to meet need), suggesting that in this context, the stages of care proposed by Tronto's (1993) model may not be sequential, but are simultaneous and overlapping practices, each of which act upon the other.

In the context of living with a parent at the end of life, it is perhaps difficult to imagine physical acts of care taking place without the presence of emotion, for example; fear, sadness, anger, hope, love. Studies of young people who have a parent with a life-limiting condition illustrate how the strong emotional bonds between family members act as a conduit for care (Kennedy and Lloyd-Williams, 2009; Phillips and Lewis, 2015), and draw attention to the effort involved in regulating emotions for both care givers and care receivers (Evans and Thomas, 2009).

The potential for carers to experience the physical act of caring for another as an emotional burden has been explored in research on family care at the end of life (De Korte-Verhoef et al., 2014; Morris et al., 2015; Whittingham et al., 2013). However, the nuanced interplay between actions and emotions and the relational context in which these activities take place are seldom explored in depth in the end of life care literature. Similarly, Evans and Thomas (2009) point out that empirical studies of family care from an ethic of care perspective often overlook the centrality of emotion to the practice of care, focussing instead on the moral value of care and the material, social and political constraints that militate against the provision of 'good' care. Wilson et al. (2012) draw on Smart's (2007) work in noting that an analysis of family practices that excludes reference to their emotional significance potentially 'flattens' data and may fail to

capture the full meaning of 'what the young people said and how they said it' (Wilson et al., 2012: 125).

The accounts of young people in this study were frequently suffused by the presence of emotion; therefore I concur with the assessment by Wilson et al. (2012) that it is important to consider the affective dimension of family practices, including practices of care between family members. In the following extracts I provide some examples of ways in which emotion featured in young people's accounts of living with a parent at the end of life and consider how the emotional practice of care can shed light on the everyday doing of family for young people in these circumstances.

Care as an emotional practice

For some young people, the emotional dimension of care appeared to constitute an ever present backdrop against which everyday life is enacted:

> *Other people can go home and spend time with their families without worrying about them, but young carers need to always worry about what's going to happen.* (Jess, 17)

> *It's like, exhausting and upsetting, knowing like my Mum can't do much stuff. Like we need to do it for her; but like, obviously that's fine with us because we are helping my Mum*. (Ellie, 16)

Parental illness was presented as a constant source of troubling emotion for Jess and Ellie. Ellie counterbalanced the distress caused by her Mum's deteriorating health with the assertion that her involvement in physical care is 'fine', suggesting that it constitutes the proper thing to do in these difficult circumstances. This resonates with research on young people living with parental substance misuse, where involvement in care was sometimes seen as one way for young people to exercise a degree of agency and to bolster their self-esteem. Providing care for a parent may therefore sometimes act as a source of support in getting on with it, albeit

one 'borne of necessity and not necessarily welcomed' (Backett-Milburn et al., 2008: 467).

For other young people, emotional distress was associated with particular events; often witnessing their parent in pain, or being confronted with their vulnerability:

> *Night times are not exactly my favourite time of day. It's like 'Oh yeah, sleep', and we're up at night. It's like when my Mum's at her worst and - I hate seeing her in pain and that's when she's in the most pain. It takes her about five, ten minutes to walk upstairs and by the time she's got to the top she's about crying.*
>
> (Joe, 13)

> *At times I've been worried. I've never been constantly worried but at times, yeah. If she's fallen, you know, like fallen over or something, like tripped up or something. You just want to – you're just a bit, oh – you just want to make sure she's alright and everything.*
>
> (James, 17)

> *First day I didn't go and see her (in the hospice). That night I completely freaked out cos, it was all sorts of things playing on my mind, like I think my main thing was, you know, that's the kind of place I'm going to end up in when – the worst happens*.
>
> (Luke, 17)

These scenarios triggered anxiety in young people, both for their parent and for themselves. Whilst young people experienced empathy for their parent, manifestations of illness and vulnerability served as a portent of the inevitable decline in their parent's health, prompting Luke to look ahead to his Mum's death and to 'freak out'.

Smart (2007) has written about the importance of emotions to the act of remembering and imagining family, and proposed the use of concepts such as memory and imaginary as useful tools for building on a practices approach. Unlike physical practices, memory and imaginary are not

contained in the present but offer the potential to traverse temporal boundaries between the past, present and future. When parental illness is experienced through the emotional practice of care, the powerful reverberations of memory and imaginary can result in a young person feeling overwhelmed. Jay provided an example of this:

> *There was a time when I sometimes sat down with my Mum and I'd think, 'Ok what will happen if my Mum dies?' Them moments really used to scare me because my imagination always got, instead of it being more towards reality, it always got really off reality and it would just scare me.* (Jay, 17)

During these particularly difficult moments, Jay's imaginary future detracted from his ability to get on with everyday life in the present. Sometimes he was returned to the present by the need to provide practical care for his Mum; 'My Mum tells me something, 'Go and do this'.' In this instance, the necessity of providing practical care acted as a counterbalance to the weight of emotional care for a young person and helped them to keep going.

Whilst imagining the death of a parent is undoubtedly distressing, young people's ability to imagine a future for themselves beyond their parent's death often provided a source of hope and resolution with which to counteract fear and anxiety. I will return to this point in Chapter Six, where the potential of the imagined future to act as a resource for young people to draw on will be explored.

The troubling emotions experienced by young people with a parent at the end of life, both for their parent and themselves, sometimes led to troubling behaviour. In Luke's account, he went on to explain what happened on the occasion he 'freaked out':

> *When you're in that kind of mood and you're down you think about everything wrong, the negative; and - I just freaked out…I stormed upstairs and I ended up punching a wall and - sat there crying like a girl {laughs}, which wasn't great, but - I can't sit here and say I know*

> *how to deal with stuff like this cos I've got no idea. Nobody does really.* (Luke, 18)

For Dan, his Mum's diagnosis triggered a change in his behaviour at school:

> *At first it didn't really upset me cos I didn't at that point, I probably didn't even know what cancer was, but then when my Dad went into it and explained what it was and everything that started to upset me and that's when I changed. School and everything. I used to never get in trouble but then when I found out I began getting in trouble a lot more.* (Dan, 16)

Luke and Dan described how acknowledging the seriousness of parental illness triggered emotions that were troubling for them. The (lack of) recognition and response to young people's experiences of the emotional dimension of care may result in behaviours that are regarded as troublesome by others and lead to young people being defined as troubled themselves (Ribbens McCarthy et al., 2013a), with implications for the types of support and services young people are able to access. Young people's experiences of the ways in which schools and colleges respond to their difficult circumstances will be explored in more detail in Chapter Six.

For some young people whose parent's illness was at an advanced stage, end of life care services were involved and there was less young people could do themselves in terms of physical care; thus attentiveness to their parent's needs began to take the form of *being with* them, offering emotional support, companionship and love:

> *It's like emotional in the sense that we don't talk but we just spend time with each other. I think like a lot of the time we do spend together outside is just sitting there relaxing and occasionally saying something every other minute or, not constantly chatting really. I mean, he gets tired so he can't constantly be chatting to anyone like that, it wouldn't be possible, but it's all, you know, we've often done*

that anyway, just spent periods when we're not actually talking but just sharing with each other, I guess. (Elliot, 18)

I'll sit on the sofa and the TV will be on, or music will be on or something, and she'll sleep and I'll just sit there and play on my phone, or watch the TV or whatever's on. If she wants something, if she wants an ice lolly I'll get it, or fizzy water or whatever. Obviously as it's got more severe, she's sleeping say twenty-two hours a day. If she needs anything I'll be there. (Lauren, 21)

The examples illustrate the centrality of emotional care to the experience of living with a parent at the end of life. In the advanced stage of their parent's illness, *being with*; the emotional practice of attending to and accompanying their parent, may be the final act of care young people are able to provide.

Having considered the significance of care as an emotional practice in the everyday lives of young people with a parent at the end of life, I turn now to explore physical practices of care, and to consider the everyday routines and actions that constitute family care for young people when they are living with parental illness.

Care as a physical practice

The social policy research on young people who take on caring roles in the family has tended to focus on classifying and quantifying the physical practice of care for a family member, and to regard the emotional practice of care as an outcome of young people's caring activities (Joseph et al., 2009; Hounsell, 2013) Consequently, involvement in tasks such as housework or the provision of personal care for a family member is often presented as the most salient aspect of family care for young people.

As I have discussed, all of the young people in the current study provided a significant amount of emotional care in attending to their ill parent and to other family members. However, the amount of physical care carried out by young people varied considerably; some young people performed

very few caring activities whilst for others, the physical practice of care occupied a substantial amount of their daily lives.

For example, James's involvement in physical care consisted of helping his Mum with tasks that require physical strength:

> *My Mum does like the cooking and the cleaning, and I come in and do all the really - I'll move all the heavy stuff. I just come in when she asks for help really. I'd start helping with all the physical things, like picking up all the shopping and sorting the shopping out.*
>
> (James, 17)

Dan and Joe reported that they sometimes 'help out' with chores around the house:

> *We all help out washing up, shopping, doing the clothes and everything.* (Dan, 16)

> *We'll do the washing up and we'll sometimes put the clothes in the washer but it's not, like often that we do that.* (Joe, 13)

In these examples, young people's contribution to household chores appeared to be no more onerous than that of any young person living with their family. In contrast, at certain points in his life Jay has provided a substantial amount of practical care:

> *After my grandparents had gone, I would wake up earlier, have to make everything myself, find things, find my Mum's medicine then make my Mum's food. Wake my Mum up; give it to her then leave for school. I'd wake up about half five, maybe a bit later, to get my Mum's stuff ready as well. Then come back from school, do all the chores really, then, I still don't know how to cook but my Mum would sit here or in a chair over there and she'd say, 'Ok, put this in first into the saucepan then do this, and that's how you make it'.*
>
> (Jay, 17)

Similarly, Lauren has been her Mum's main carer throughout her illness, even though at the time of her interview, her caring role consisted primarily of *being with* her Mum. Young people's differential involvement in the physical practice of care can be related to the availability of others who can offer support. Five of the ten young people in the study live with both parents, and in these circumstances the parent who is not ill tended to provide more care. For example, Elliot described how the care of his Dad has been taken on by his Mum:

> *In terms of helping my Dad, my Mum obviously does help him a lot more. She's got a lot of experience in care, you know, that's the career she's vaguely been in her whole career.* (Elliot, 18)

Ellie lives with one parent and her siblings. Her Gran lives nearby:

> *My Gran helps my Mum a lot, so my Gran's usually there to help but she doesn't do anything in the house because she also has her own house and all that, but she'll take care of my Mum, make sure she's ok.* (Ellie, 16)

Ellie's Gran appears to have taken on the emotional and physical care of her Mum, but cannot manage household tasks as well, so these have become the responsibility of Ellie and her siblings.

Three young people live alone with their parent. James's Mum is still able to do most of the practical care of the house and the family, but for Jay and Lauren, when their parent's health began to deteriorate, they found themselves with limited support from other adults. Even so, neither has cared for their parent entirely on their own; Jay's grandparents moved in with the family temporarily and took over many of the physical and emotional tasks of caring for his Mum:

> *After my grandma came, she did everything. Literally whatever I had to do, I didn't need to do any more… and my grandfather was like a person whom my Mum could go and talk to whenever she wanted.*
>
> (Jay, 17)

Lauren has 'a very close extended family', many of whom live at a distance, but one of her aunts has regularly travelled to the family home to share the care of Lauren's Mum:

> *My aunty comes up so we split – cos I think it's, it is very hard. You do need a break. So when I'm there [aunt] can go back, and you know, go for an Indian with her boyfriend, go and have a few drinks and relax, and then when she's here, me and [boyfriend] can go out*.
>
> (Lauren, 21)

For Lauren and Jay, one of the most troubling aspects of the physical practice of care has been addressing their parent's need for intimate personal care:

> *There were some things that I couldn't do, like if my Mum needed a bath or a clean or something like that, or a shower. I felt that I can't actually do this and my Mum would somehow have to manage. Then my grandma came over and that was literally all gone.*
>
> (Jay, 17)

> *[Home care service] come in and, if you want, they can help you get washed and dressed and things. It's easier when the nurses and that go in. If there's something she wanted that she didn't want me to do, they do it.* (Lauren, 21)

Jay clearly stated that he feels unable to provide personal care for his Mum, but Lauren referred instead to her Mum's perceived discomfort at having to rely on her daughter for intimate care. These quotes illustrate how gender and generation interact to impact on culturally defined expectations of normative care practices. These expectations influence young people's sensibilities with regard to the provision of intimate care and affect the relationships of care between a young person and a parent at the end of life. Further reflections on the gendered nature of care provided by young people can be found later in this chapter.

The provision of intimate personal care for a parent by a young person has been identified as troubling in the literature on young carers, in that it disrupts the normative boundary that limits physical intimacy between a young person and their parent (Aldridge and Becker, 1993; Earley et al., 2007). However, Clarke and O'Dell (2013) warn against applying a social policy discourse of young carers to make sense of the care provided by young people when a parent has support needs. They make the point that research from within the policy field of young carers risks pathologising family care by obfuscating individual and family experiences and overlooking the way in which 'personal troubles…are partly shaped by service structures and policy frames' (2013: 81). I will return to consider the impact of services based on a young carers' discourse on the experiences of young people with a parent at the end of life in Chapter Six.

It must be acknowledged that some young people with a parent at the end of life sometimes find their involvement in family care troubling, but this appears to be primarily as a consequence of the emotional dimension of care practices, rather than the physical labour of care work. For example, Ellie said:

> *It's not easy - the day to day, like just looking after my Mum, and living - with the illness… it's the emotional part. Yeah, it will always be the emotional part.* (Ellie, 16)

The accounts of young people in the current study indicate that involvement in the physical practice of care when a parent is at the end of life varies considerably depending on the context in which care takes place. When there are fewer adults on hand, young people are more likely to provide higher levels of physical care, demonstrating the importance of wider networks of care to determining young people's experiences of family with a parent at the end of life. Nevertheless, it is their experience of care as an emotional practice that appears to be most challenging for young people when they have a parent at the end of life, and which is

inexorably woven into their everyday experience of living with parental illness.

In the following section, I develop the analysis of communication in families with a parent at the end of life to consider communication as an exemplar of the *care-full* practice of family, in which emotional and physical practices of care are integrated. I examine how young people demonstrate agency in 'doing talking' based on their affective understanding of the needs of family members and themselves.

5.2.3. Communication as a *care-full* practice

In the previous chapter, I explored how practices of communication between family members can shed light on young people's everyday experiences of family when a parent is at the end of life. In particular, I suggested that the ability to moderate the timing and content of information they receive about their parent's illness is important in helping young people to get on with their everyday lives.

In this section, I suggest that communication between family members can be seen as an example of how the emotional and physical practices of care are interrelated for young people with a parent at the end of life. In addition, young people's deliberations with regard to communication exemplify care as a relational and a moral practice, manifested in and through everyday family life.

Young people in the current study referred to the way in which family members do talking as evidence of the presence or absence of care:

> *Mum's best friend, she's been really good, you know. She texts Mum, calls Mum every single day. She texts me now every single day too, making sure I'm alright and that.* (Lauren, 21)

> *I've never really gone on how much you see somebody cos obviously they've got their own lives sort of thing, but even a simple text every now and then - my Mum's side of the family, she doesn't always get*

> *that…I mean [friend's mum], she's good friends with my Mum. She'll message my Mum near enough every day, which drives my Mum mad but it proves she cares, and sometimes I feel like they care more than the family does.* (Luke, 18)

Young people value regular communication as a sign of care, especially when it is not possible for distant others to be physically present. The act of communicating via regular telephone calls or texts can be interpreted as both a physical practice of *caring for* and an emotional practice of *caring about* (Ungerson, 1983) the young person and their parent. Furthermore, communication has a moral value, in that young people have a sense of what family members *should* do with regard to keeping in contact, and are aware of when individuals have not communicated in the proper manner.

The multiple perspectives approach adopted in this study suggests that normative ideals with regard to communication practices are generationally defined; young people cited frequent text messages as an indicator of 'good' care, whereas some parents appeared to regard them as a nuisance. For example, Pete (the partner of an ill parent) said:

> *There's one concern with [partner] with text messages, people texting her and her dealing with that before she'd deal with anything with us, and I'd got to the point where I'd say to her, "Tell them, 'Sorry I'm busy at the minute'." I was that mad that somebody else could by just a simple text message could change our mood so quickly. I try and say to her, 'Look it will go, leave it. Don't answer it till tomorrow'. It feels like people have now got you on a tap. They can have your mood, your emotions just by text messaging every single part of the day. I just feel like throwing the thing at the wall.* (Pete)

The difference in expectations and preferences with regard to practices of communication suggests that there may be a generation gap, whereby adults do not always appreciate the importance of regular contact to

young people's experience of being cared for when they have a parent at the end of life.

Young people's accounts also provide examples of their own deliberations with regard to communication; for example, Dan explained how he tries to gauge his parents' emotional state before he communicates with them:

> *When you're in with the family, you have to be careful what you say because it can upset Mum, or you don't realise what you've said and that's the main reason why arguments get caused. It's cos we've not thought before what we've said...When Dad's in a bad mood then you just, you're quiet, you don't say anything; whereas when he's in a good mood you can speak to him. Same with my Mum really.*
>
> (Dan, 16)

Elliot has chosen not to talk to his Dad about his illness because he thinks it will be difficult for him:

> *I've tended to speak more to my Mum about it because, I think just because she knows as much as him about it, and it's much easier for him to not talk about what's happening to him...I haven't spoken to my Dad about how he feels in a while. I think I've only ever done it properly once, cos I've never really known when to time it, and I am going to talk to my Mum about how to time it and what sort of mood to ask him in.* (Elliot, 18)

The interviews with significant others included numerous instances of where parents sought to moderate their communication with young people in order to avoid causing distress. Here, my focus is on the perspectives of young people and my intention is to demonstrate that young people are equally aware of the emotional significance of communication in their relationships with family members, and consequently engage in deliberative, *care-full* practices of speaking and remaining silent.

Overall, young people's accounts of communication between family members act as a lens through which the relational practices of doing family when a parent is at the end of life can be viewed. Young people make on-going judgements about *when* to talk about *what*, *to whom*, and *how*; and in doing so, reveal the dynamics of care as an emotional and a physical practice enacted in and through relationships with others. Furthermore, in deliberating about the proper thing to do with regard to communication, young people reveal care as a moral practice, one which is informed by wider social and cultural narratives concerning the role of family and friends in facilitating a good death.

Having explored how young people talk about care in their accounts of everyday family life and considered the meaning of care as it is manifested in young people's narratives of living with a parent at the end of life, I turn now to the negotiation of care. In the following section, I examine the processes whereby young people navigate their involvement in care when they have a parent at the end of life and the practices that shape young people's decision-making in this context.

5.3. NEGOTIATING CARE

Finch and Mason's (1993) study of family and kin relationships set out to investigate whether there is a consensus regarding the proper thing to do in relation to offering support to family members and significant others. The study revealed that with the exception of a parent's responsibility for the care of children, there is little consensus around the proper thing to do; however, there appears to be a greater consensus around how to work out the proper thing to do and the underlying principles that inform decision-making in this context. Finch and Mason's work thus sheds light on the process and practice of negotiation between family members and reveals how moral identities are constructed through the changing dynamics of responsibility in family relationships.

In this section, I examine the negotiations that take place in families when a parent is at the end of life and give particular consideration to young

people's involvement in negotiating care practices. Whilst Finch and Mason's study concerned negotiations between adults, other researchers have investigated the role of children and young people in negotiating the proper thing to do, particularly following parental separation or divorce (Smart et al., 2001; Brannen et al., 2000). These studies indicate that far from being passive recipients of care, young people are moral agents, actively engaged in negotiating practices of care to meet the support needs of family members. I begin by discussing some examples of the way in which young people and family members negotiate the responsibility to provide care when a parent is at the end of life.

5.3.1. The process and practice of negotiation

Some young people gave relatively straightforward examples of ways in which they work out their responsibility to care for others through discussions with family members:

> *I think we all have an equal role in everything, with everything that goes off...Normally we just volunteer someone. Yeah, each day it's different. '[Brother] you're doing it' and then he'll get up and do it, and then it will be 'Dan you're doing it' so I get up and do it. Arguments might break out but that very rarely happens.*
>
> (Dan, 16)

> *I do always feel able to approach her and ask what she needs doing. If she doesn't really want anything doing or helping, she has to constantly say so. We kind of have a mutual agreement that that's ok and we won't get wound up with each other, and that we will be honest when we want some help, and if we just want to be left alone that we'll say so.* (Elliot, 18)

Dan and Elliot described a process of open, verbal negotiation to determine who takes on what, although in Elliot's example, the overall responsibility for care is located with his Mum. Finch and Mason (1993) suggest this form of open negotiation between adults is sometimes

presented as a means of demonstrating the family is responding to a crisis in the proper manner by rallying round to offer support. Both Dan and Elliott appeared to be presenting a similar moral tale of family by emphasising that any potential conflict is minimised during the course of these negotiations. In practice, the range of possible outcomes from these discussions may be limited; young people may risk a threat to their moral identity as 'good' sons or daughters if they do not agree to take on their share of care, and there may be few alternatives available to resolve the need for care in that there may be no-one else living in the family home.

Nevertheless, the notion of fairness and of everyone 'doing their bit' is an implicit feature of many accounts. In the following extract, Luke expresses his disapproval of an uncle who does not appear to help his Dad care for Luke's Nana:

> *I've got a couple of uncles on that side. [Uncle's] the oldest but he has nothing to do with my Nana really, doesn't do anything to help. I don't know; it's like he don't care. He's the eldest, my Dad's the youngest, but my Dad does most.* (Luke, 18)

Luke suggested that birth order is relevant in negotiating responsibility, and that older siblings in particular should be willing to take on their share. Joe also criticised his older sibling for not taking responsibility to care for himself:

> *[Brother] gets back from work, then he'll go and see his girlfriend, which irritates my Dad cos my Dad has to do all his ironing and make his lunch for the next day. Him, he's twenty, twenty-one, I don't know what, something like that age. I don't know, but he should be doing it by himself.* (Joe, 13)

One principle that appears to inform young people's negotiations in the context of family is therefore concerned with family members taking on their fair share of the responsibility for care according to their age and ability. The symbolic value of this form of equal and open negotiation between family members is demonstrated by Ellie:

Ellie: *We don't usually get on but [Mum's illness] has like brought us closer.*

Nicola: *In what way has it made you closer?*

Ellie: *We like help each other - that's basically it.*

Nicola: *How would you help each other?*

Ellie: *Taking care of my Mum, doing the housework, doing like jobs for her, going to the shops, walking the dogs.*

Nicola: *So do you do those things together?*

Ellie: *Yeah, or sometimes we take turns.*

Nicola: *So how do you work out who's going to do what?*

Ellie: *We just like say, like I'll do it this week and [sibling] can do it next week and [sibling] can do it the week after.*

(Ellie, 16)

According to Ellie, the practice of negotiating responsibility for her Mum's care with her siblings has 'brought them closer'. Ellie's account does not suggest that 'closeness' in this context implies a strong emotional bond. It appears instead that the act of negotiation exemplifies a degree of communication and co-operation previously lacking in their relationship, but recognised by Ellie as having taken on a new significance in the context of living with parental illness. Ellie is perhaps responding to the implicit discourse of family pulling together to provide care at the end of life, and in referring to practices of negotiation is demonstrating that she belongs to a 'close' family; defined here as a family that is continuing to function and to care for its members.

Open negotiation as one means of determining responsibility for care draws on notions of fairness, equality and mutuality, which can be applied by young people to create or sustain a sense of family during difficult circumstances. A less explicit form of negotiation based on the notion of reciprocity has also been identified as an important guiding principle in determining the proper thing to do (Finch & Mason, 1993; Sevenhuijsen, 2003). These researchers emphasise that reciprocity of care may occur in a number of ways; for example, it may involve shifts in care practices over

the life course, the exchange of different forms of care, or an individual caring for a family member who has not directly cared for them.

Examples of reciprocity can be identified in young people's accounts where a family member who is giving care to an ill parent receives care from a young person:

> *I do a lot of things for my Mum like little errands, cos obviously she'd much rather stay at home with my Dad than go out and do some shopping.* (Elliot, 18)

> *My Dad helps out quite a lot with my Nana, but he's turned round and said that he can't cope with keep going down there with everything that's going on at home, saying he struggles and stuff like that...When I go, I do stuff for her, like help with her shopping and everything like that.* (Dan, 16)

Elliott and Dan reflect an understanding that taking responsibility to provide care for other family members increases the potential for better care for their parent at the end of life. This suggests some level of understanding of the interdependency of family members and their embeddedness in a fluid network of care givers and care receivers.

The notion of family as a nexus of relationships characterised by reciprocities of care reflects the concept of care developed by care ethicists, in which care is a relational practice and an expression of interdependency (Barnes, 2012; Sevenhuijsen, 1998; Tronto, 1993). This iteration of family care contrasts with the dyadic model most often employed in end of life care research (Harrop et al., 2014; Henriksson and Årestedt, 2013; De Korte-Verhoef et al., 2014), which tends to obscure the networks of inter- and intra-generational care embedded in families.

As well as receiving care, young people in the current study provided care for their siblings, their ill parent and other family members. The recognition that reciprocities of care in families are more complex and nuanced than the dominant model of family care in end of life care implies

could support the development of a different approach to investigating family care which recognises the involvement of all family members, including young people.

In this section, I have considered examples of where young people have been explicitly or implicitly involved in negotiating the responsibility for care when they have a parent at the end of life, and highlighted some of the principles and processes applied by young people in working out the proper thing to do. In the following section, I explore the presentation of care as an obligation in young people's accounts and examine the implications for young people's agency when they are living with a parent at the end of life.

5.3.2. Care as an obligation

The notion that young people are obliged to provide care for a parent at the end of life evokes an interpretation of family as founded on a generational contract, whereby young people *must* take care of their parents when they become old or are otherwise in need of support. Funk's (2015) study of adult children caring for elderly parents illustrates how the generational contract is both acknowledged and resisted, and explores the impact of the tension between obligation and choice on both the practice of care and the self-identity of adult children.

Caring for a parent at the end of life was described in terms of fulfilling a generational contract by some young people in this study. For example, in the following extract Lauren presents caring for her Mum as a form of 'paying back' the care she has received in the past:

> *She would do anything for me and [sibling], anything; and I think that shows cos we'd do anything for her as well. We were always very close...I came home one day and I was like, 'Mum, I'm allowed on the New York trip. You know, £750 and it's got to be paid in 3 weeks'. She would go, 'Ok here's the money', but she would have a sandwich that*

night instead of having, you know. She would do anything for you.

(Lauren, 21)

Lauren's sense that she owes it to her Mum to provide care for her implies that the responsibility to care for a parent at the end of life is non-negotiable, and is a duty rather than a choice. However, Lauren simultaneously resists the inference that care is an obligation, qualifying her explanation with references to fairness and the close emotional bond she shares with her Mum. She went on to say:

She sleeps a lot, but I'll still sit down with her in case she needs anything or wants anything, cos like I said, I know that if the tables were turned she'd do it all for me so I think that's fair. Not fair, I didn't do it to be fair; I do it cos I love her. (Lauren, 21)

In Funk's (2015) study she reports, 'participants frequently referred to relational qualities such as love and affection in explaining why they wanted to help, contrasting these against ideas of duty, responsibility and obligation' (2015; 392). Funk attributes this to the perceived associations of the latter concepts with the notion of caring as a burden, and suggests that participants were keen to avoid the possibility of their actions and relationships being interpreted in a negative light. However, she goes on to suggest that a strong familial ideal of unconditional love, such as is present in Lauren's account, precludes the possibility of choosing not to care, and therefore choice in this context differs little in practice from obligation.

The issue of choice in relation to care is directly addressed by Lauren when she explains her decision not to return to university to complete her final year, but to remain at home in order to care for her Mum:

It was an easy decision to make. If I could choose between Mum and an education, I'd choose Mum, so it wasn't a hard choice. ..She was going, 'Oh, go to uni. I don't want your life to change' and I was like, 'No', cos if something does happen, I don't want to look back a year and say, 'I wish I'd had that time'. (Lauren, 21)

If Lauren had not made the decision to return home, it is unclear who would have provided day to day care for her Mum, since there are no other family members close at hand. Lauren's decision was therefore made in the absence of other readily identifiable sources of family support. Lauren may also want to avoid the risk of being seen as selfish or uncaring which a decision to return to university may have incurred.

Studies of the way in which adults negotiate family relationships following divorce or separation indicate that declining the commitment to care bears a moral consequence for adults (Philip, 2014; Ribbens McCarthy et al., 2000), but the extent to which this also applies to young people is less evident. The moral imperative for parents to care for children does not have a direct equivalent for young people, although I suggest that there is a competing moral imperative for family members to care for those who are dying. It therefore seems plausible that Lauren may wish to be, and to be seen as, a 'good' daughter through her decision to remain at home and care for her Mum.

Furthermore, although presented as a choice, Lauren is ultimately not choosing 'between Mum and an education' since although she can continue her education in the future, she cannot continue her relationship with the physical presence of her Mum beyond her Mum's death. Instead, Lauren is reflecting her wish to spend time with her Mum while she can; a desire shared by Elliot, who has also chosen to remain at home rather than going away to university:

> *I'm living at home for this year. Originally I'd wanted to leave and go to uni...but as soon as this was the situation, I wasn't going to move away, because it would be stupid to leave for three years when one of the people you live with has a year left to live roughly.* (Elliot, 18)

These extracts further exemplify the point by Wilson et al. (2012) that young people's accounts of disruption in their everyday family lives carry a deep emotional resonance that may be overlooked by an approach that focuses on practices alone. The emotional commitment demonstrated by

Lauren and Elliot expresses a sense of belonging and connection that conflicts with the neo-liberal model of family generally iterated through policy frameworks and applied by health sciences research in end of life care. In this literature, there is often a presumption that family members are autonomous individuals and family life is governed by a process of independent decision-making. Instead, young people's accounts of living with a parent at the end of life illustrate how decisions are made on the basis of close and interdependent relationships with others and as such, accepting the responsibility to care is perhaps best characterised as responding to an obligation rather than as making a choice. As Funk (2015) suggests, 'truly self-interested actions are limited in relationship with others, in which love can compel one to help as an automatic response, particularly during times of need or in the absence of other sources of help' (2015: 393).

Young people do demonstrate some room for manoeuvre in their everyday experiences of family life through their descriptions of negotiating the allocation of caring activities between family members. In doing so, young people may be responding to a dominant neo-liberal social discourse in which the exercise of personal autonomy and choice is valued and privileged (Barnes, 2012); but in practice, their choices with regard to taking responsibility for care when they have a parent at the end of life are often bounded by their status as young people.

Limitations on young people's agency relate in part to their structural position as children; young people in the study are substantively dependent on their parents and most are not in a position to leave the family home. As I have pointed out, five out of ten young people live in households with no other adults; three of whom have no siblings. The lack of availability of other providers of family care raises the moral stakes for young people who may wish to avoid taking responsibility for care to the extent that young people living away from home may feel obliged to return. However, I suggest that the decision to return or to provide care is indicative of the strength and tenacity of the bonds between family

members and an expression of what Smart (2007: 45) terms 'embeddedness', such that belonging to a family is akin to 'being a part of one' (Smart, 2007: 45). Viewing young people's experiences of care through this lens sheds light on the emotional weight of living with a parent at the end of life evident in young people's accounts of their everyday lives and brings into focus the emotional significance of care as an obligation.

Wilson et al. (2012) borrow Smart's (2007: 43) notion of 'embeddedness' to explore how living in difficult circumstances threatens both young people's experiences of family and their idealised notion of family and induces 'strong feelings of yearning and loss' (Wilson et al., 2012: 126). I suggest that in providing care for a parent at the end of life, young people are seeking to maintain family and to sustain a sense of belonging and embeddedness that supports the ontological security 'being a part of one' may provide. As a consequence, the emotional and physical care practices of young people with a parent at the end of life can be construed not only as meeting the obligation imposed by a generational contract, but also as care of the self. I will return to the interplay of caring for others and care of the self later in this chapter (section 4.3.), but first I continue to explore the concepts of responsibility, choice and obligation by considering whether young people's accounts of living with a parent at the end of life suggest that gender is a factor in shaping practices of care.

5.3.3. Care as gendered

The conceptual development of care as a gendered practice has been elaborated in Chapter Two (section 2.5.5.). Finch and Mason's (1993) study found that women were far more likely than men to accept the responsibility for providing personal care for a family member via a process of 'non-decision making' (1993: 74). This process refers to arrangements for care that 'just emerge', without any discernible form of explicit or implicit negotiation. Finch and Mason (1993) suggest that women's biographies are more likely to position them as care-givers, and

therefore when care is required women are regarded as best placed to provide it. They point out that this form of responsibility for care develops over time and builds on previous negotiations, reputations and moral identities established throughout the life course. The effect is to reinforce the gendered distribution of care; but this can only be perpetuated if the commitment to care is transmitted across generations, such that the biographies of young women continue to be disproportionately characterised by care.

In this study, Jess provided the most explicit example of the intergenerational transfer of the commitment to care. She described her role within the family as follows:

> *I was brought up to help her. I was always brought up to help - that's all I remember is always being brought up to help my Mum around the house, doing things. I've always learned how to look after myself and my [siblings].* (Jess, 17)

Jess and her siblings have been living with their Mum's illness for at least ten years. It appears that Jess has been responding to the care needs of her family members since early childhood and the responsibility to care has become an enduring aspect of her biography.

Whilst this non-negotiable commitment to care was most clearly expressed in the accounts of Jess and of Lauren (where it is presented as an expression of love), none of the young men in the study rejected the responsibility to care or implied that caring was not consistent with their identity as sons and brothers. However, with the exception of Jay and Elliot, the physical care carried out by young men was accommodated relatively easily into their everyday lives, being no more than most young people living at home would contribute to family life. Where gender appeared relevant to the practice of care, it was related to young men's perception that their physical strength meant they were better able to carry out certain tasks; for example, James carrying heavy shopping bags or Elliot lifting his Dad:

> *I'm a bit stronger than my Mum, so if my Dad's legs have completely gone and you're having to lift his whole weight I am kind of more useful.* (Elliot, 18)

In general, gender appeared to be less of a factor in determining young people's involvement in care than the availability of alternative providers of support. Five of the seven young men in the study lived with both parents, whereas all three of the young women lived with only the parent who was at the end of life. As has been discussed, where another adult was available, they carried out the majority of physical care in the household. Here, gender was salient in that this tended to be presented as a change in roles for young people's parents when it was their mother who was ill and their father providing care (Matt, p. 154), but as a consolidation of the caring role when it involved their mother caring for their father (Elliot, p. 166).

The experience of everyday family life where a father was taking more responsibility for care may have been a factor that contributed to the way in which young men in the study assimilated the practice of care into their own lives. However, it should also be noted that none of the young men in the study had sisters who were living at home who may have been expected to step in to provide care when their parent became ill, therefore any caring activities had to be undertaken by men in the family. Elliot described how his sister, who lives away from home with her boyfriend, is keen to move so that she can be nearer to her parents:

> *Once everything had changed that kind of was it. They wanted to move down eventually cos they wanted to have a kid near their families as well...but erm, now it's sped up the process a bit really*. (Elliot, 18)

In contrast, Lauren has a brother who also lives away from home, but has been substantially protected from the impact of his Mum's illness:

> *The thing is with [brother] is that Mum only ever tells him what she want to tell him. He only ever knows half the story because obviously,*

> *she doesn't want him to be sat worrying, or she didn't want it to change any of our lives. So she didn't tell [brother] because I think he would have been back more if he had known everything.*
>
> (Lauren, 21)

Lauren's Mum's decision to protect her brother has absolved him from any obligation to fulfil a generational contract with regard to providing care, but has also contributed to the considerable change Lauren has experienced in her everyday life.

Overall, the small number of participants and of permutations of family in this study limit the observations that can be made with regard to the impact of gender on the care practices of young people with a parent at the end of life. However, young people's differential involvement in care appears to lend support to Bowlby's (2012) assertion that gender norms in relation to family care are often only shifted where women's availability is limited. In these circumstances young men stepped in to undertake caring activities even when (as in Jay's case) this involved significant change to their everyday lives. Furthermore, the emotional practice of care appeared to be less influenced by gender; both young women and young men demonstrated a strong emotional response to their parent's need for care and a commitment to maintaining family through the emotional practice of care when living with a parent at the end of life.

In this section I have explored how young people and family members make decisions concerning practices of care in families with a parent at the end of life. I have considered notions of negotiation and obligation in relation to family care with reference to concepts of fairness, reciprocity and embeddedness in the context of an understanding of family as a set of interdependent relationships and commitments. In addition, the inference that family members are working out the proper thing to do in their everyday lives through the practice of care has highlighted the significance of care as a moral practice. Barnes (2012) points out that

whilst the way in which the responsibility for care is enacted will depend on the particular context of the relationship, to fail to take any responsibility for care would generally confer moral judgement. I suggest that in working out practices of care, young people are acting as moral agents and are sustaining individual and familial moral reputations by responding to parental illness in the proper manner.

In the following section, I further develop the analysis of care as a moral practice by exploring in more detail the form and function of moral tales in young people's accounts of family care when they have a parent at the end of life.

5.4. TELLING TALES OF SELF AND FAMILY THROUGH NARRATIVES OF CARE

Having examined the language and concepts young people draw upon to talk about care and the processes applied in negotiating the practice of care in young people's everyday lives, my aim in this section is to look beneath the surface of care as a family practice to explore the moral significance of care in the everyday lives of young people with a parent at the end of life. In this section, I consider the way in which care shapes the identities of young people and gives meaning to their relationships with others as sons and daughters; sisters and brothers. I explore how descriptions of care in young people's accounts reveal tensions in relationships between family members, and highlight some of the strategies young people adopt to resolve tensions and assist in getting on with their everyday lives.

This discussion draws on an understanding of care as a moral practice, bringing into focus the practice of care as a means of navigating the moral terrain of family life. Feminist researchers have drawn attention to the significance of family as a key site for the formation and enactment of adult moral identities through negotiating the proper thing to do in relation to children (Finch, 1989; Ribbens McCarthy et al., 2000), but there has been less scrutiny of how living with an adult who has support

needs may impact on the moral identities of other family members; in particular, for young people. This section will explore how care of self is interwoven with care of others in young people's accounts of living with a parent at the end of life and the moral tales of caring for children /caring for the dying revealed through practices of care.

First, I begin by considering how young people express their sense of self in the context of living in a family with a parent at the end of life, and how the identity of a young person may be influenced by the shifting dynamics of care between family members.

5.4.1. Tales of being a carer

Empirical studies of young carers have suggested that the emerging identities of children and young people are influenced by their involvement in caring for a family member, such that young people assimilate the role of 'carer' into their concept of self and this may impact on subsequent life choices; for example, choice of career (Earley et al., 2007; Rose and Cohen, 2010).

As indicated in the previous section, Jess provided the most explicit example of the practice of care having been integrated into her sense of self in the current study. Not only has Jess expressed her intention of taking on parental responsibility for her siblings (Jess, p. 157), she also said she would like to work as 'like a social carer' in the future.

Jess is one of two participants who were recruited via a young carers' project. She has received support from the project over a period of ten years, and it is possible that her contact with the service has provided her with a language and a conceptual framework with which she can narrate her account of everyday life. She sums up her experience of living with a parent at the end of life as follows:

> *People don't know what it's about. They just think a young carer is just a young carer. They don't know what you go through.*
>
> (Jess, 17)

Jess's identity as a young carer sets her apart from other people, but this is counterbalanced by her sense of solidarity with other young carers:

> *They get you better than people that don't know what you're doing. They get what's happening.* (Jess, 17)

Identifying as a young carer thus had negative and positive consequences for Jess characterised by feelings of otherness and belonging.

I suggest that for Jess, her developing concept of herself and her identity within and outside of her family has been informed not only by the practice of care in her everyday life, but also by the interpretation of these care practices through the support services she has received. The tendency for young carers to be 'othered' as 'children in need' through a policy-driven definition and interpretation of young people's involvement in care has been noted (O'Dell et al., 2010; Rose and Cohen, 2010) and may limit the available narratives with which young people can tell their own tales of family life. I will continue to explore this point in Chapter Six (section 6.3.3.).

Lauren also refers to herself as a carer in her account of living with parental illness. Again, the adoption of this identity appeared to have been prompted by the intervention of an external agency; in this case the Department for Work and Pensions:

> *I get Carers' Allowance. I didn't really want to do that because it felt like I was doing it for money then and I wasn't, but it did help. Mum told me to do it. She said, 'If you're doing this, it's a bad thing, then it's fair if you get something good from it'.* (Lauren, 21)

Lauren appeared ambivalent towards her receipt of Carers' Allowance because it conflicted with her narrative of care as an expression of the close emotional bond she shares with her Mum. The implication that she may be 'doing it for money' posed a threat to her moral identity as a loving daughter; assuaged by her Mum's assurance that it is 'fair' for Lauren to receive some recompense for her care labour. The

characterisation of Lauren's involvement in care as 'a bad thing' is perhaps a reflection of the negative feelings her Mum experiences as a result of needing Lauren's support, and of the challenge this poses to her own moral identity as a good mother.

Lauren's ambivalence towards assuming the identity of a carer, and her wish to present her involvement in care as a positive, moral choice, are threads that are woven throughout her account of everyday family life. Lauren described the practice of caring for her Mum as follows:

> *The time that we spend together has changed, but the way that we interact - it just feels like we're spending time together. It doesn't feel like I'm caring for her, even when it's, you know, 'Can you get me this? Can you do this?' It's something that I would have done even if she wasn't sick, so I don't think anything really changed, and I don't feel like a carer.* (Lauren, 21)

Lauren sought to minimise the impact caring for her Mum has had on her life and resist being identified as a carer. It may be that Lauren wants to emphasise that the essential quality of her relationship with her Mum, 'the way we interact', has remained consistent, even though the dynamic of care has shifted. Lauren may also be seeking to protect her Mum's moral identity through rejecting the notion of being her carer, and therefore distancing her Mum from the negative moral consequences of being dependent on her daughter. In addition, Lauren may wish to demonstrate her rejection of an interpretation of care as an obligation and a burden as opposed to a moral choice and an expression of her relationship with her Mum (Funk, 2015).

Studies of family care at the end of life have illustrated how a sense of responsibility for meeting the needs of others may be accompanied by ambivalence in relation to the practice of care, or towards those who need care. This has been attributed to the moral contradiction between what family members feel about providing care, and what they believe they *should* feel (Smith, 2009), or to the tension between responding to

another's needs and acknowledging their own need for care (Harding and Higginson, 2001). Lauren's account suggests that tension and ambivalence also feature in young people's experiences of living with a parent at the end of life. For some young people, such as Jess, the identity of 'young carer' may offer a resolution by providing a moral framework in which the practice of care is interpreted and validated as the proper thing to do in response to living in difficult circumstances.

For others, such as Lauren, the identity of young carer is in itself a source of ambivalence. The rhetoric of costs and benefits often employed in policy-driven research on young carers, with its emphasis on the effort expended and outcomes achieved, may be experienced as incongruent with an understanding of care as a relational practice underpinned by reciprocity, mutuality and emotional commitment. This contrast between the use of the term 'young carer' in relation to the self in the accounts of Jess and of Lauren suggests that public discourses on family care may have a positive or a negative influence on young people's sense of themselves, their family members and their involvement in care, and may need to be applied with caution when seeking to understand the experience of living with a parent at the end of life.

In Jay's account, the threads of this discourse on care as hard labour, and on those who need care as dependent and therefore burdensome, are woven into a different moral tale:

> *I see myself as like - basically when my Mum goes somewhere or if she's ill, I'd rather prefer that I'm alone rather than go [to stay with family], cos then I think of myself as a burden to them. You know, I think that they'd have to look after me, they'd have to feed me, they'd have to take me places, and I would just think of myself as a burden.*
>
> (Jay, 17)

Far from regarding the care he provides for his Mum as burdensome, Jay is concerned that his own ongoing need for support renders him a burden to extended family members, and even to his Mum:

> *I know my Mum needs me but I also know that my Mum would get better treatment [abroad] than she does here. I know that the only reason my Mum's here is because I'm here and she has to look after me.* (Jay, 17)

Jay appeared unable to adopt a positive identity for himself through care-giving, or to use the practice of care to navigate around his experience of ambivalence; instead Jay constructed a negative identity for himself as 'a burden'. Jay presented an account in which the tension between being both a giver and a receiver of care created a moral dilemma he was unable to resolve, since accepting the proper thing to do from his perspective would be detrimental to his own well-being.

Later in this chapter, I explore some examples of how young people try to balance the need to care for others with the provision of care for the self. Here, a consideration of the broader cultural narratives of family care and the way in which these are applied in young people's accounts of living with a parent at the end of life illustrates how the moral identities of young people are shaped in response to prevalent understandings of the dynamic between 'carer' and 'cared for'. In the following section, I explore how the practice of care reveals tensions when the shifting identities of family members come into conflict, and consider whose narrative of family prevails when family members' perspectives on care differ.

5.4.2. Conflicting tales of 'care'

In her study of sibling care in older age, Barnes (2012a) observes that family relationships change as care needs increase, and that 'care giving can lead to conflict and stress as well as being experienced as an act of love' (2012a: 9). Barnes acknowledges that care can have a 'dark side'; one which has been exposed through recent enquiries into the abuse suffered by people in residential facilities at the hands of paid carers (e.g. Mid Staffordshire NHS Foundation Trust, 2013). Whilst this may represent an extreme violation of the principles of 'care', the extent to which care-giving may be conflated with notions of protection, control

and coercion has been raised by others (Tronto, 1993; Williams, 2012) and merits further consideration.

In the context of family care, Brannen and Heptinstall (2003) write, 'Delivered in the 'best interests' of the child or elderly person, care is represented as 'love' while the power which is exercised is silenced or treated as invisible' (2003: 184). In this section, I draw on the multiple perspectives of one family in the current study to explore how the notion of best interests is elaborated through the practice of care when a parent is at the end of life. This particular family provided an illustration of how care can be a source of conflict, and may be experienced as coercion or control. In attending to the gaps and overlaps between the narratives of family members, my aim is to shed light on the moral deliberations involved in the balancing of best interests for young people when they are living with a parent at the end of life.

Luke's account of the occasion on which he and his Mum (Shelley) argued was discussed earlier in this chapter (Luke, p. 156), where I suggested that Luke was troubled by his sense of needing to take more responsibility for his Mum. Luke appeared to perceive that his Mum was no longer able to act in her own best interests and that in caring for her, family members needed to make decisions on her behalf in order to protect her from harm. Luke told another story in order to illustrate his Mum's diminished capacity to assess the proper thing to do:

> *She knows she's ill but I suppose it's possibly 'ignorance is bliss'. She's always trying, she'll be stood up on there dusting, knowing that she only has to slip slightly or go dizzy, which she has done before, and she'll fall. She's very likely to break her hip and - it's doubtful she'd recover from that, but you can't tell her that. She'll do it again and again.* (Luke, 18)

This account bears striking similarities to the description of an incident recounted by Luke's Dad (Pete):

> *I went to football last week, came back early. She's stood on there and she's dusting up there. Because of where her cancer is, if she slipped off there, she'd probably break her hip and I'm sorry to say they're never going to mend that. These are the things you try and explain to her. These are the important things she does realise, but she cannot recognise that threat to her well-being at the stage she is now.* (Pete)

It appears that this story has been shared between family members as a 'cautionary tale'; a warning of what may happen if they do not act to protect Shelley. She, meanwhile, is troubled by the loss of her position in the family as a wife and a mother:

> *A lot's changed. I don't feel as though I've got that role any more. Erm, 'No you're not doing this. No you're not doing that'. Pete's taken, everything's taken away and I'm trying to get it back, but he's finding it hard. You see, he took over the Mum role a little bit when I had the breast cancer and then he's reluctant to give it me back.*
>
> (Shelley)

Shelley's account illustrated how her resistance to the shift in roles and responsibilities between family members has impacted on her moral identity:

> *I'm being selfish, because they want a longer time with me, but I'm being selfish by wanting to be a Mum and a wife because if I do that, it might speed the cancer up or I might do something to make it worse. Then they're going to be without me, so I'm torn*.
>
> (Shelley)

Shelley has tried to weigh up the best interests of herself and her family in deciding on 'the proper thing to do', and is torn between wanting the opportunity to express her identity and wanting to be around for her family for as long as possible.

These accounts point to the significance of care as a moral practice, in which deliberations with regard to the practice of care are made in and through relationships with others. However, the moral consequences of decisions may not be equally borne. In this example, it appears that Shelley accepted the charge of being 'selfish' and endeavoured to live with a form of care that did not take into account her expressed need to maintain her position in the family, and therefore failed to meet Tronto's (1993) criterion of 'responsiveness'.

In setting these accounts in opposition to each other, it is perhaps easy to arrive at an understanding of 'good' care as an entitlement to be negotiated between individuals, albeit in relationships characterised by emotional commitment and interdependency. Attempting to balance the care needs of family members may lead to conflict, in which 'winners' shape the moral tales that inform individual accounts of everyday life. However, focussing on Luke's perspective perhaps offers a different interpretation.

Luke's narrative of acting in his Mum's best interests took the form of a moral tale in which he is concerned with protecting his Mum, but he is also acting to preserve the well-being of his family by ensuring she is present and available to them for as long as possible. Ribbens McCarthy (2012) posits a version of the self which is 'more than, or different from a set of individuals-in-relationships; well-being is bound up with the unit, since 'We are one' – 'the social person'' (2012: 79). She suggests that this view of selfhood is more often associated with circumstances in which 'the collective sense of personhood that underlies 'the social person' may perhaps be seen as a realistic response to the uncertainties of survival' (2012: 83).

For a young person with a parent at the end of life, the death of a parent may be seen as a threat to the survival of family and therefore to 'the very point of origin of the self' (Wilson et al., 2012: 126 quoting from Illouz, 2007). This perspective draws on Mason's (2004) conceptual model of

relationality as a continuum, *more* or *less* focused on the individual, and of agency and identity as relationally constituted. From this perspective, Luke's narrative may be interpreted in the light of Ribbens McCarthy's (2012) comment; 'when we focus on 'family' discourse and practices, we may find that for some people, in some contexts, the individual is really not relevant at all, since 'family' is understood as a unit that is indeed greater than the sum of its individual parts' (2012: 85). Navigating best interests from this perspective may therefore be less concerned with negotiating between individuals-in-relationships and more concerned with taking into account the embedded relationality of family. Luke, in seeking to put the best interests of family first, may be reflecting his sense that the moral significance of family is greater than the best interests of individual family members.

In the following section, I elaborate on the notion of care as being delivered in the best interests of family by exploring ways in which young people talk about care of the self in relation to care of others when they have a parent at the end of life.

5.4.3 Tales of caring for the 'self-and-others'

The study of step-parenting by Ribbens McCarthy et al. (2000) discusses some examples of where parents (particularly fathers) by-pass the moral imperative for families to put the needs of children first by presenting an alternative moral duty of care for the self. The duty of care for the self is presented as an individualistic discourse, in which moral issues are framed as irrelevant since the adult's survival depends upon taking care of the self. In order to avoid telling an immoral tale, the accounts of fathers in the study did not allude to the presence of dependent children, who would have a greater claim on the duty of families to provide care.

Tales of caring for the self were present in young people's accounts of living with a parent at the end of life, but were often juxtaposed with references to caring for others. One example can be found in Luke's description of using humour as a means of getting on with everyday life:

> *I suppose if I make fun of it and have a laugh about it; it's not quite so bad. I'd rather be happy with the time I've got than mope about, cos, sounds awful but if she passed away tomorrow I'd sooner I'd spent the day before having a laugh rather than moping, thinking - she's going to die at some point. I mean obviously it plays on your mind but, I'd rather not show it. I'd rather when she eventually goes into the hospice and what not, rather I've given her something to remember rather than, 'I've put my kids through hell' sort of thing.*
>
> (Luke, 18)

Luke's strategy of injecting humour into his everyday experience of family life not only helped him to manage his own feelings, but also provided a more positive experience for his Mum. Luke's account demonstrates how the emotions engendered by living with a parent at the end of life can lead to taking action that supports both care for the self and care for the ill parent. Another example is provided by Elliot:

> *I don't struggle with those moments where I'm helping him but when I think back about them I always wonder why I don't cos I mean, regularly I'm there lifting my Dad who is physically unable to walk if I don't do so, and you know, when I'm helping to lift him up I can also feel his nerves constantly tightening and untightening which must be agony and it's - I can just detach myself from it, not in a completely weird and uncaring way but I can just cope with it, and I think because I know that if I start worrying about it, obviously that won't be nice for him.* (Elliot, 18)

Elliot has found a way of putting his emotions aside in order to concentrate on providing competent care for his Dad, but at the same time, this enables Elliot to manage a situation he may otherwise experience as a 'struggle'.

These examples illustrate how the emotional work of living with a parent at the end of life does not impact on young people as autonomous individuals, but is experienced and enacted through the relational practice

of care. Young people may respond to their difficult circumstances by practicing care for both the self and others, but these are not mutually exclusive fields of care; care for the self can be achieved through care of others and vice versa.

This manifestation of care for the *self-and-others* may be particularly pertinent for young people when they have a parent at the end of life. As the moral imperative for families to meet the needs of vulnerable members shifts from the young person towards the parent who is dying, the potential to care for the self by caring for others may enable young people to make up for any 'deficit' in care whilst avoiding the risk of their actions being interpreted as 'selfish'.

An alternative reading of the practice of care for the *self-and-others* draws on Ribbens McCarthy's (2012) iteration of 'the social self'. In particular, Ribbens McCarthy writes, 'Close identification and fused boundaries within a group such as family may lead, not to enmeshment, but to 'close knit selves' (Kağitçibaşi, 2005: 411), which do not undermine the agentic self, constituting instead a form of relational autonomy' (2012: 80).

The conflation of care of the self and care of others in the accounts of young people with a parent at the end of life may be one way in which 'close knit selves' are expressed through everyday family practices. From this perspective, young people are not attempting to balance care of the self with care of others, but are employing a relational autonomy to act in ways that promote the best interests of family, rather than its individual members. The study by Wilson et al. (2012) suggests that even when family life is lived out in difficult circumstances, the sense of belonging and connection young people seek in family is not readily available to them elsewhere. For young people with a parent at the end of life, the care of *self-and-others* may be a product of, and a means of sustaining the 'embeddedness' that is associated with being part of a family as their parent's illness progresses.

5.5. CONCLUSION

In this chapter, I have discussed the meaning, practice and moral significance of care in young people's accounts of living with a parent at the end of life. Young people's narratives depict care as a fundamental and ubiquitous feature of family lives; it is in and through the practice of care that family is constituted and enacted in young people's everyday lives. In the context of living with a parent at the end of life, care also functions as a lens through which to view the shifting dynamics of family relationships and the endeavours of young people to get on with their lives in changing and challenging circumstances.

Young people's accounts of living with a parent at the end of life suggest a complex and nuanced interpretation of care as an overlapping series of emotional and physical practices underpinned by notions of interdependence, reciprocity and emotional commitment. The separation of care into *caring about* and *caring for* (Ungerson, 1983) sometimes found in the literature on family care, whether from the perspective of health studies (De Korte-Verhoef et al., 2014) or the work of care ethicists (Barnes 2012a), tends to imply that these practices can be assessed as discrete and distinct elements of care. However, in the accounts of young people's in the current study, *caring about* and *caring for* often merged. The interplay of action and emotion underscored young people' everyday lives and characterised their experiences of living with a parent at the end of life. For example, I have described how the *care-full* practice of communication by young people is indicative of how deliberative actions are informed by the emotional practice of care and by the recognition that 'doing talking' sometimes evokes troubling emotions for family members and for young people themselves.

I have described how young people and family members work out the proper thing to do in relation to providing care when a parent is at the end of life, and I have argued that whilst young people did provide examples of negotiation between family members, the opportunities for

young people to choose not to care were bounded. The act of declining to care incurs a moral cost for adults, particularly for parents (Philip, 2014), although the moral consequences for young people in the study were less apparent. I have suggested that young people with a parent at the end of life may be more invested in maintaining the idealised notion of familial love as an unconditional emotional commitment through the practice of care, given the disruptive potential of parental illness for the on-going continuity and cohesiveness of family.

I have considered how applying a sociological lens of care as a fundamentally relational and a moral practice can bring to light ways in which family members enact the deeply embedded desire to belong to a 'proper family', particularly when dealing with the changes and challenges of everyday life. Through their accounts of living with a parent at the end of life, young people were revealed as moral agents who took responsibility for their actions and made decisions on the basis of reconciling their needs with the needs of others.

As the moral compass of family life shifted away from meeting the needs of young people towards meeting the needs of their dying parent, young people in the current study found ways to integrate the care of self-and-others and to maintain the capacity of family to provide a sense of belonging during changing circumstances. The importance of preserving the integrity of family may be particularly significant for young people, who have fewer options to seek alternative forms of belonging, and whose ontological security may be most severely challenged by the imminent loss of a parent.

The interrogation of care in young people's everyday family lives in the current study indicates that, rather than being a set of discrete, dyadic relationships between a 'carer' and a 'cared for'; family is a complex nexus of interdependent relationships, in which the practice of care brings to mind Smith's (1997) paradoxical description of social capital as 'both a glue...and a lubricant' (1997: 170). I suggest that practices of care between

young people and family members function as both a glue that reinforces the emotional bonds between family members, and a lubricant that enables family practices to shift and adapt to the changing and challenging circumstances of living with a parent at the end of life.

Finally, Ribbens McCarthy (2012) warns against the risk of perpetuating a romanticised view of ideal family relationships underpinned by notions of interconnectedness and a mutuality of care. She emphasises that inequalities persist both within and between families, and that individuals and families have different access to social and material resources. These inequalities may influence the practice of care in families and determine the options available to support the well-being of family members. I examine this point in relation to young people living with a parent at the end of life in the following chapter, where I consider the social and material resources employed by young people in getting on with their everyday lives when a parent is dying.

CHAPTER SIX: RESOURCES

6.1. INTRODUCTION

In my discussion of the research findings for this study of the everyday lives of young people with a parent at the end of life, I have focussed so far on the major themes of young people's experiences of family and of care. In Chapter Four, I drew attention to the routines and practices that support young people in *getting on with it* and continuing with their everyday lives in the context of a family whose members do not always meet the idealised notion of being there for them. Chapter Five examined how young people's involvement in caring for others can be interpreted as a means by which young people care for the self, and therefore *keep going*. Through caring for the self-and-others, young people counterbalance the competing moral demands for family to care for young people and to care for the dying, thus minimising the moral and existential risk posed by belonging to a family that fails to act in the proper manner.

The everyday doing of family, including the routines and practices of giving and receiving care, therefore acts as a resource for young people in responding to the difficult circumstances of living with a parent at the end of life. Young people are not merely passive beneficiaries of this support, but actively exercise agency in shaping the practices that contribute to maintaining everyday family lives and engendering a sense of continuity during the often extended period of change and uncertainty that follows the diagnosis of a life-limiting parental illness.

In this chapter, I further develop this analysis by turning attention to the resources outside of a young person's family that are drawn on and utilised in the context of *getting on with it* when a parent is at the end of life. As I discussed in the literature review (Chapter Two), examinations of the theory and practice of 'coping' in the context of death and dying often apply the concept of resilience to understanding how people respond to

significant loss (Monroe and Oliviere, 2007; Sandler et al., 2007). Sandler et al. (2007) suggest that there has been a tendency within this literature to focus on intra-personal attributes and to overlook the importance of wider environmental factors in building resilience. In contrast, and in keeping with the sociological approach adopted by this study, my focus here is on the inter-personal and institutional resources young people employ in 'deflecting, minimising or amplifying the trouble loss brings' (Jamieson and Highet, 2013: 135).

I begin by exploring the role of friends and *like family* relationships in young people's everyday lives, and then examine young people's contact with and use of services when they have a parent at the end of life. Finally, I explore young people's agency in getting on with their everyday lives by examining how young people talk about the future when they are living with a parent at the end of life. In her study of young people following parental bereavement, Ribbens McCarthy (2007) suggests that one way in which young people display agency is through attributing meaning to events in their lives. In this final section, I explore how young people make sense of parental illness in relation to their own lives, and how young people's accounts of the future shed light on the process of meaning-making as it is lived out in young people's everyday lives.

6.2. FRIENDS AND *LIKE FAMILY* RELATIONSHIPS

Youth has been theorised as a social category marked by an increase in autonomy and independence from family ties (Gillies, 2000), in which the process of transition towards adulthood is enacted through young people's relationships with others and with social institutions such as education and employment (Henderson et al., 2007; Kehily, 2006). In relation to the family, it is normatively assumed that young people will begin to spend less time with family members and more time with friends, and that friends will occupy an increasingly significant place in young people's everyday lives (Cotterell, 2007).

In the current study, following on from biological relatives and others who were defined as family, young people described friends as the people who are most important to them:

> *I've got my friends at school. I see them Monday to Friday; they're all pretty local. Then I've got some friends outside of school that I kind of see weekly, you know, weekly at the weekends*. (James, 17)

> *I've got [friends] through football; there's a lot of people who care for me through that. I've got people through that that are there all year round, sort of thing*. (Luke, 18)

> *Right now I've got friends that I met the day I moved up here*. (Lauren, 21)

As I discussed in Chapter Four, some young people equated their friendships with family relationships, describing friends as 'like family'. Friendships appeared to offer young people a sense of closeness, care and *being there* that mirrored family relationships, or sometimes acted as a substitute for family relationships when these characteristics were not easily discernible in the young person's family. As Jay explained:

> *They are the people who are supporting me as much as my real family. Sometimes if it comes down to something, friends will support you a little bit, but these have supported me even though it's not their family. It's my Mum, not their Mum, and for me they were a lot of support. Where my Mum's brother, it's just the complete opposite.* (Jay, 17)

Friendships appeared to act as a resource for young people in two distinct ways: firstly, young people described talking to their friends about their everyday experiences and the challenges of living with parental illness; secondly, young people reported gaining some respite from living with parental illness through socialising with friends.

6.2.1. Talking about living with parental illness

Having someone to talk to about their experience of parental illness appeared to be important to young people in the current study. Research on the impact of parental bereavement on young people suggests that talking with friends functions as an enabling mechanism in dealing with loss through the provision of both emotional and informational support (Dopp and Cain, 2012). However, there has been little scrutiny of how talking with friends is experienced by young people living with a parent at the end of life; Philips and Lewis (2015) describe the support received by young people outside of the family in their qualitative study as 'minimal', but go on to state, 'When peers were able to provide support, it seemed to help a great deal' (2015: 855).

Young people in the current study often reported seeking out friends for emotional support when they were challenged by their experience of parental illness:

> *I always go to my friends. Yeah, they know everything, like everything; and just when I hear things I tell them, because they'll be there and they'll just sit and listen.* (Ellie, 16)

> *I'll talk to [friend] a lot. If I've got a problem, he's probably one of the first people I'd ask cos he offers it. He says, 'If you ever need to talk'. It's like today, I went and talked to him about something to do with football and we ended up going on about all sorts of stuff. Erm, so any problems I've had I'll discuss with him, and we'll just sit talking for ages.* (Luke, 18)

> *I told them, like I just came out and said, cos they could notice that I was feeling more down and everything when I was at school. I wasn't the happy chappy that I was - they could tell and everything, so they just asked me and I told them, but nobody else really.* (Dan, 16)

The difference between the minimal use of friends for emotional support in Phillips and Lewis's (2015) study and the frequent references to talking

with friends in the current study may be related to the age of participants. In Phillips and Lewis's study, participants were aged 11-15, and the authors suggest that their friends were simply not equipped to offer adequate support. Only one young person in the current study fell within this age range, and he was the only participant who did not regard friendship as significant:

> *I've got friends yeah, but - they're not like really important.*
>
> (Joe, 13)

It is possible that Joe's age meant that he has not yet had sufficient time or opportunity to develop a strong network of friends outside of the family, and he acknowledged generally finding it difficult to talk about his Mum's illness. Consequently, he preferred to spend time with his family, where he felt supported without the need to talk:

> *We're all going through the same thing really so, for us all to like sit down and talk about it, cos that's something I wouldn't do; I can't do that. I can't sit there and have a heart to heart. I struggle to do it, but like we all know kind of how each other is feeling*. (Joe, 13)

The accounts of young people in the current study suggest that it is not simply the availability of friends that is important to young people with a parent at the end of life, but also the quality of their friendships. Young people exercise agency in assessing their friendships and making decisions about who they talk to, as the above quotes by Luke and Dan illustrate. Young people often described being selective about which friends they approached for support and generally only confided in a small number of close friends:

> *I'd talk to some of my friends, you know. I'd say, yeah, not all, but it's the ones I'd trust, so to speak*. (James, 17)

> *Some of my friends do know. There's only one but, well two that I'm really, three that know, cos I'm really close to them, and I can speak about it with them...yeah, there's only the three.* (Dan, 16)

> *I'll usually just find a friend to come round cos a couple of my - not all my friends know, cos I wanted to tell everyone in person, and I just ended up not getting round to telling everyone because it was either awkward, or I didn't really want to.* (Elliot, 18)

One factor young people take into account in deciding who they talk to about their family lives is their assessment of whether friends have the emotional resources to listen and respond to their concerns. Just as young people practice *care-full* communication with family members, they are also sensitive to the potential for friends to be distressed by their everyday experience of living with dying, and therefore they take care over seeking support for themselves. Elliot's reference to encounters with friends sometimes feeling 'awkward' was reflected in other accounts:

> *Well I don't really talk about it. I kind of go, 'Yeh, she's alright', because like I said, there's only so much you can say at the pub isn't there? You don't want to go, 'Actually she's this, this and that', you know, cos everyone goes, 'Oh', you know, and it makes them feel awkward.* (Lauren, 21)

Young people appear to take on the additional responsibility of anticipating and protecting their friends' feelings, thereby increasing the already considerable emotional labour undertaken by young people with a parent at the end of life. Sometimes this additional work entailed young people offering support to their friends:

> *Sometimes [my friends] find it upsetting but obviously I tell them, 'Don't', because some of them are close to my Mum, and they're just upset and like, they can't - like nothing can help her anymore, and they hate seeing me upset and also hate seeing my Mum upset.* (Ellie, 16)

At a time when young people want to talk to friends about their experience of parental illness, the potential for these everyday encounters with dying and death to trouble others may act as a barrier to seeking

support and generate further troubles for young people in terms of having to *care-fully* manage the disclosure of their concerns.

A further difficulty encountered by young people in talking to their friends is that their peers do not always react in a manner perceived as helpful; therefore in deciding who to approach, young people also took care to protect themselves from troubling responses:

> *You don't know how they'll react to it or anything like that, cos you get some people they just turn their back and think, 'I don't give a crap, so why are you telling me?' Then some people are like, 'Ah, bless you', and stuff like this. In a way both don't make it better.*
>
> (Dan, 16)

> *People do ask, 'How are you doing? How's your Mum doing?' kind of thing, but no-one really looks at me, you know, in pity or sadness. We all just have a laugh still*. (Lauren, 21)

These quotes indicate that young people do not wish to be pitied or patronised by their friends as a consequence of living with parental illness, and imply the rejection of a 'harm story' with its associated status of victimhood (Ribbens McCarthy et al., 2013a: 11). Jamieson and Highet (2013) describe how young people who have been parentally bereaved shape their narratives in the context of a social discourse of parental death as a 'tragic loss' (2013: 136). The tendency for living with a life-limiting illness to be constructed as a period of 'pre-bereavement' (Chowns, 2010; Fearnley, 2015) or 'pre-death' (Popplestone-Helm and Helm, 2009) may lead to the super-imposition of these discourses of tragic loss, harm and victimhood on the everyday experience of living with a parent at the end of life, and confer on young people a social identity they may not choose for themselves.

The accounts of young people in the current study suggest that young people value the relationships they have with friends and do not want to be 'othered' by their experiences (Ribbens McCarthy et al. 2013a: 2). Lauren expressed this as follows:

> *I don't want people to act differently. I don't want people to, you know, shy away. Every time they go, 'How's your Mum doing? Is she OK? How are you doing?' I hate that question {laughs}. I liked how I was with my friends, so I don't really want it to change*.
>
> (Lauren, 21)

Lauren's interactions with friends sometimes left her with a sense of being perceived or treated differently because of her experience of parental illness. Jess explained why she has hardly spoken to her friends since 'Mum got worse':

> Jess: *I need to fake how I feel with my friends so they don't need to ask what's up.*
>
> Nicola: *Why is it that you don't want them to ask what's up?*
>
> Jess: *I don't want anyone to see my emotions, cos nobody can help. There's no point talking about it.* (Jess, 17)

Jess appears to be protecting both herself and her friends from the troubling emotions engendered by parental illness. Whilst this protection is achieved at the cost of 'faking' how she feels, Jess avoids attracting sympathy and therefore being defined as damaged by her experiences. Since 'nobody can help', Jess may perceive the potential to be assigned the status of victim as a form of entrapment. In Chapter Four, I discussed how Jess intends to take responsibility for her siblings after her Mum's death, and it is possible that in this context, she is more concerned with demonstrating her competence and ability to deal with the difficulties she encounters than in risking the appearance of vulnerability by seeking emotional support.

Jess's avoidance of her friends suggests that whilst friends can act as a resource, the maintenance of friendships can be troubling for young people when they are living in difficult circumstances. Young people's experiences of friendship therefore reflect the ambivalence and ambiguity that characterises *a new normal* in the everyday lives of young people with a parent at the end of life.

Some young people respond to the ambiguity of friendship as a resource for providing emotional support by identifying a particular friend who had already had a similar experience:

> *There's an old friend; sometimes I speak to her about it because she's in the same situation, but her Dad's like - he can get treatment, but like he's still ill.* (Ellie, 16)

> *My friend [name] has been outside of the family the person that's supported me the most...He's got experience of close family members who needed assistance and care. Yeah, he's been a nice person to have around and you know, he's I think the only friend it's never really in any way a sort of issue to bring round, because you don't think about, 'Oh do we need to keep out the way', or any of that, cos he kind of just instinctively knows how to not make a hassle.*
>
> (Elliot, 18)

> *I speak to my friend [name]. Her Mum passed away two years ago, or a year and a half ago, and I talk to her about it sometimes because she's been through it. I just want some guidance, you know, what to do sometimes and when to do it and things like that*.
>
> (Lauren, 21)

This form of friendship based on shared experiences and support received in the context of an equitable relationship is more congruent with peer support as it is defined in health care settings (Dennis, 2003). The practice of facilitating peer support is well established as a strategy for promoting young people's health and well-being (Turner, 1999). I will continue to explore how young people in the current study use peer support later in this chapter. However, it is notable here that young people are often adept at identifying people within their social networks who are able to offer support based on their own experiences, and that this support may be both emotional and informational.

Finally, three young people in the study named their girlfriend or boyfriend as a person who has been particularly supportive towards them:

> *You know any problems I have, I can talk to [girlfriend] any time and it's mutual sort of thing. I mean, obviously like any relationship we have problems, but - she's incredibly supportive and, yeah, it's like having my own - I suppose in a way she's always on hand. She'll always make time for me.* (Luke, 18)

> *Over the last few years, my girlfriend, if there's anything I want to talk to her about, I would; and if it was anything that my parents should worry about, she'd be letting them know {laughs}. So there's me thinking that I'd just told her and that they weren't finding out, and I found out that they are.* (Matt, 20)

> *[Boyfriend] moved in because we wanted to spend time with each other, but I couldn't really leave Mum...He's there through it all as well. He's a really good support for me*. (Lauren, 21)

Matt and Lauren's descriptions of these significant relationships challenge the notion of young people's developing intimacy with another as being an important marker of the transition towards a more autonomous and independent adult identity (Robb, 2006). In these accounts, young people describe how their girl/boyfriend has become incorporated into the everyday experience of family with a parent at the end of life, *moving in* towards the family rather than facilitating the young person *moving out*. Matt's girlfriend has been talking to his parents about Matt's concerns in an effort to ensure that they can act together to support him. Lauren's boyfriend has physically moved into the family home to provide Lauren with practical as well as emotional support in caring for her Mum. It appears that the recognition of the young person's interdependence with family members in the specific context of living with a parent at the end of life informs the manner in which young people practice intimate relationships in this context.

Gillies (2000) has problematised the theory of youth as a period of transition, arguing that it obscures the emotional and material dependence many young people continue to share with family members throughout their lives. She calls for, 'a more integrated analysis of family relationships as a set of concurring or meshed individual life-courses' (2000: 223); an approach more congruent with an ethic of care perspective. I suggest that this analysis of the meanings of friendships and intimate relationships for young people in the current study is an example of how viewing everyday lives from the perspective of young people with a parent at the end of life can inform understandings of young people (and adults) as embedded in a shifting web of interdependent relationships within and between generations.

In this section, I have explored how the opportunity provided by friends to talk about their everyday experiences of family life functions as a resource for young people with a parent at the end of life. I now consider the role of friends in enabling young people to gain some respite from their difficult circumstances.

6.2.2. Taking a break from parental illness

For some young people, time with friends is valued as free time away from the routines and practices of living with a parent at the end of life. This appeared to be particularly important for young people who are providing a lot of physical care for their ill parent at home. For example, Jay described going to college as an opportunity to spend time with his friends:

> *People go to college to learn things. I didn't go there to learn things; I went there to actually be happy. My Mum being ill, I wasn't able to get out and meet my friends, you know, go to the movies, go to the cinema with my friends or maybe even just go out with my friends to go out to the park, just messing about like every kid does sometime in his life. I was able to do that in college, but I didn't have enough time to do that outside*. (Jay, 17)

Jay's college routine gives him a break from looking after his Mum and affords him a social life he would not be able to sustain otherwise. Later, Jay added:

> *If my friends hadn't been there, it would've been that, you know, I'd have sat there just thinking about my Mum at home, and thinking what is going to happen, which was quite difficult for me*.
>
> (Jay, 17)

Friendships therefore enable young people to take their mind off their parent's illness and reduce the emotional labour of living with a parent at the end of life, albeit temporarily. Since the emotional practice of care is experienced as the most troubling aspect of their everyday experiences for young people in the current study (see Chapter Five), the value of friendship as a form of distraction is significant. Elliot summed up the restorative benefits of simply spending time with friends:

> *I tend to, if I ever do feel kind of bad and want to do something about it, call up friends and just hang around with one of them, and to be honest, usually within about half an hour I'll be feeling much better.*
>
> (Elliot, 18)

In the following quotes, Dan and Luke explain how belonging to a football team helps them:

> *I think if we didn't have football we wouldn't have been able to cope and everything, cos it just, it took your mind of it and everything. You'd just go and think, 'Football, right. What do I need to go and do?' and everything. You wouldn't think about anything*. (Dan, 16)

> *You know, whenever possible I try not to over think stuff. It's like at football, I don't overly think about my Mum, which sounds awful but, when I can, I put it to the back of my mind cos' it allows me to concentrate on other stuff. It's never gone, but it's not the main thing, sort of thing.* (Luke, 18)

This resonates with Kennedy and Lloyd-Williams's (2009) qualitative study of young people living with a parent with advanced cancer, in which they found that being distracted by friends was the most common form of 'coping' reported by young people. Kennedy and Lloyd-Williams suggest that meeting up with friends enables young people to 'maintain normality' (2009: 891). However, as I discussed in Chapter Four (Family), 'normality' is often experienced as uncertain and ambiguous by young people with a parent at the end of life, many of whom cannot remember a time before parental illness.

It is possible that spending time with friends allows young people to enact a practice normatively associated with being a young person, and therefore supports the performance of a moral tale concerning how young people *should* divide their time between friends and family. However, the accounts of young people in the current study suggest that it is the opportunity to think, feel and act *outside* the 'normality' of parental illness that young people value in relation to their social activities. Therefore, rather than 'maintaining normality', meeting up with friends appears to offer young people a break from the new normality of living with dying.

Whilst young people appreciate time with friends as a distraction from living with a parent at the end of life, it is also enjoyable, as Jay emphasised in his description of 'a proper friend'.

> *A proper friend like properly cares about you, and you know that they do, and it's not just that you speak to them, you have fun with them*. (Jay, 17)

It is perhaps important to note that social activities are not necessarily solely or primarily instrumental in supporting young people with their experience of parental illness, or chosen by young people on that basis. I suggest that within the uncertain context of living with a parent at the end of life, young people actively engage with friendships and activities that provide meaning and purpose to their lives beyond the everyday routines

and practices of family life. For example, Luke went on to explain how football is more than a distraction for him; it is his passion:

> *I suppose when I think about it, the main thing I think about is football, which I don't know whether that is because I'm trying to not think about everything else, but I've got a massive interest in it, and I love it - It's what I think about most of the time.* (Luke, 18)

The tendency to view the actions of young people with a parent at the end of life through the conceptual lens of 'coping' privileges the construction of young people as victims, and therefore risks 'othering' young people who are living with this particular form of family troubles (Ribbens McCarthy et al., 2013). Instead of interpreting young people's friendships as primarily a resource for 'coping', it may be that young people value time with friends 'for predominantly social (as opposed to 'social work') reasons' (Cree et al. 2002: 49). Luke concluded:

> *You know, there's always going to be something horrible in your life. It's just how life works, but it's important to have something that makes you happy as well.* (Luke, 18)

In this section, I have addressed a gap in the literature on young people living with a parent at the end of life, in which there is little of an exploratory nature that considers the meaning and practice of friendship from the perspective of young people themselves. I have argued that young people value talking with friends, but often undertake emotional labour in maintaining friendships in difficult circumstances and identifying friends who may be best placed to offer support. Social activities with friends provide some respite from living with a parent at the end of life, but are also enjoyable in themselves. Young people exercise agency in pursuing activities that provide meaning and a sense of purpose beyond the experience of parental illness, and in doing so actively challenge the discourse of tragic loss and the status of victimhood it confers.

In the following section, I turn to how young people make use of services and consider whether the current policy and practice framework in end of life care facilitates access to resources by young people when they have a parent at the end of life.

6.3. STATUTORY AND VOLUNTARY SERVICES

In this section, I explore how young people engage with services provided by the statutory or voluntary sector; in particular, services that are intended to enhance the well-being of people at the end of life and their family members, or to promote the well-being of young people more generally. This discussion draws on Kittay's (1999) observation that relationships of care between family members take place within a set of nested dependencies, wherein the ability of family members to access additional support is shaped by the availability of wider resources, which is in turn determined by the socioeconomic context in which services are provided. The broader context of care between family members is sometimes referred to as the 'carescape' (Bowlby, 2012: 2112), denoting the economic, political, social and technical terrain in which interdependent practices of care are situated.

This section explores the social and material resources provided to young people in the current study by a range of service providers, examines young people's routes into accessing services and considers some of the wider policy and socioeconomic factors that shape the availability of services for young people when they have a parent at the end of life. I begin by examining the support provided to young people by their school or college.

6.3.1. Young people's education services

Since full-time education is compulsory for all children between the ages of 5 and 16 in the UK, the education system is the largest statutory provider of services to children and young people, and is therefore well placed to reach young people who may require support in dealing with a

range of difficult circumstances (Patel et al., 2007). Seven young people in the current study were in, or had recently completed, compulsory education; three young people were attending higher education institutions.

A young person's school or college was the service provider most often cited as offering support for the young person with regard to living with a parent at the end of life. Five young people had received, or been offered, counselling support from a school counsellor, and three had received support from another member of staff such as a mentor or a personal tutor. Young people appeared to regard school counselling services as a potential resource:

> *I thought I might as well go in, you know, go in open-minded and see.*
>
> (James, 17)

> *I don't have to let it out, but it helps. Cos I know if I keep it in long enough it's going to make it, make things worse really.*
>
> (Joe, 13)

James and Joe acknowledged that they found the counselling sessions helpful, but James added that he had not told any of his friends about them:

> *...cos then that would go on to like, well, 'Why?' And then, well, it would just go on and on really.* (James, 17)

This may indicate that there is a stigma attached to using school-based support (Fox and Butler, 2007), and reinforces the point that young people are careful in choosing how they inform their friends about their parent's illness.

In other accounts, young people reported negative experiences of school counselling services:

> *I used to have a counsellor but then I don't have her anymore. She wasn't really helping...so then if I'm like emotional I'll usually just sit*

there myself, or I'll go and meet up with my friends.

(Ellie, 16)

I stopped seeing [school counsellor] because I didn't think it was helping me, cos she used to beat around the bush. She never used to mention the thing that you was actually there for, she'd talk about something else, whereas when I went to [child bereavement service] it was straight to the point; 'How are you feeling? How are you coping?' and everything like that...They're not like treading on eggshells as you say. They can openly speak about it, not try and ignore the fact that it's there. (Dan, 16)

Ribbens McCarthy (2007) points out that the extent to which talking is valued as a means of expressing emotions varies between individuals and social groups, but Dan's experience also draws attention to the variance in approaches between counsellors as a factor in shaping young people's engagement with school counselling services. Studies of the efficacy of school counselling tend to produce mixed results (Cooper, 2009; Fox and Butler, 2009), and do not provide sufficient information on referral criteria to assess whether such interventions can be regarded as helpful for young people living with a parent at the end of life. However, Dan's quote indicates that some school counsellors may not be comfortable with talking to young people about their everyday experiences of living with dying.

Previous research suggests that school staff lack confidence in responding to young people who have been bereaved (Lowton and Higginson, 2003). Even though they are often the non-family member in closest contact with young people dealing with a bereavement, some school staff report that they do not have sufficient training or expertise, and sometimes struggle to manage their own feelings of distress (Lane et al., 2014). School-based responses to bereaved young people vary considerably between local authority areas, and school staff will often opt to refer a young person to a 'specialist' service, such as a child and adolescent mental health service, or

a children's bereavement service (Holland and Wilkinson, 2015; Tracey and Holland, 2008).

Whilst it is difficult to locate comparable research on school responses to young people who are living with a parent at the end of life, Dan's account implies that there may be similar factors involved in determining how schools approach the support of young people who are living with life-limiting parental illness. Dan was referred to a specialist children's bereavement service by the school when it became apparent that the school counselling service was not helping him; seemingly because the counsellor was not able to directly address Dan's particular circumstances. However, this option is not available to many young people because the availability of childhood bereavement services is limited, and many do not offer support to young people who have not yet been bereaved (Rolls and Payne, 2003). Most services are provided within the voluntary sector, where there are considerable challenges to maintaining sufficient funding, particularly during a time of decreased public spending on welfare (Rolls and Payne, 2004).

Young people's routes in to accessing services are also relevant here; Dan explained how he initially came to the attention of school staff:

> *I was getting into trouble. It was just {sighs} that was it. They never mentioned anything about what was going off at home it was just - tensions and stuff like that...I think there was one point where I was, they was on the verge of excluding me and everything.* (Dan, 16)

It was at the point where Dan was not only troubled by his experience of parental illness, but was also 'troublesome' at school that he was eventually referred for support. This raises questions about how young people access services when they have a parent at the end of life. Other young people in the current study explained that they were initially offered counselling after their parent had informed school about their circumstances:

My Mum asked school, cos I wasn't like talking to them or anything and I wanted - she wanted someone for me to talk to.

(Joe, 13)

My Mum's friends with like a teacher at school...and by those two talking, erm, the teacher got in contact with like the support system school has. (James, 17)

However, the school being aware of a parent's illness did not always lead to the young person being approached to find out if they would like any support:

I think Dad informed college but - nothing was ever said to me, that they were worried or anything like that. (Luke, 18)

Just as young people preferred to talk to only a few close friends about their parent's illness, they also made decisions about whether to approach school staff themselves:

Like I say, because I was just getting up and going and kept going, most probably half my teachers probably wouldn't have even realised what was going on at home...I'd say most people weren't, unless I did tell them, most people weren't aware of anything that was going on for me. Most people wouldn't have realised.

(Matt, 20)

I still never really had anyone come and talk to me about it, but I was never going to ask type of thing. I'm not going to ask for help sort of thing, and that's how I went up through school and college.

(Luke, 18)

Clearly schools and colleges cannot offer support to young people if they are not aware that it might be needed, but it appears that even when they have knowledge of a young person's experience of parental illness, young people are not always offered the opportunity to access support unless there is a troubling change in their behaviour.

Some young people in the current study did obtain instrumental support from school staff through more universal forms of school provision, such as personal tutors or career guidance mentors:

> *My tutor, really; he was one of the main people who knew. I'd say he was there if I needed him, that was the main thing...Most of the time he'd just, like I say, help me out with my college application, help me out with anything like that.* (Matt, 20)

> *The mentors try to help with stuff, like in the future. I might not be in college for a certain amount of days, or I might be late for a couple of days...They can help with that, but you know, if I want to speak to someone, like about what's happening at home, I can't like open myself towards them. I can't just say, 'This is everything that's happening'. I can do that with my friends, but not with the mentors.* (Jay, 17)

Jay's quote reiterates the finding that most young people would prefer to talk to their family or friends about matters that are important to therm. Elliot echoed Jay's comments:

> *I got offered counselling just for being an emotional teenager when I was at secondary school, and I didn't want to do that for the similar reason that I didn't really want to talk to someone about something that mattered to me when I didn't know them at all. If I had friends who didn't mind talking to me I'd much rather talk to friends.* (Elliot, 18)

Young people with a parent at the end of life may not want support from staff at their school or college. Nevertheless, it appears that emotional support is not always forthcoming because staff are not pro-active in making it available, leaving it to young people or their parents to ask for help instead. It is beyond the scope of the current study to determine why staff do not approach young people who are living with parental illness to offer support, but research on young people's experiences of bereavement suggest that school staff often feel ill equipped to address the sensitive

issues of dying and death with young people (Lane et al., 2014; Lowton and Higginson, 2003). As a consequence, some young people may not have access to resources that they may find helpful. For example, Luke reiterated:

> *I was never going to sit and ask, 'I need someone to talk to. Can you set me up a counsellor?' sort of thing, because I didn't want that. If I was offered it I probably would take it, or would have took it, but I was never going to ask for it.* (Luke, 18)

The reluctance to engage young people in a discussion about their support needs in the context of living with a parent at the end of life contributes to the 'conspiracy of silence' other researchers have noted in some practitioners' dealings with families when someone is dying (Fearnley, 2010: 455). In the following section, I turn to palliative and end of life care services and examine whether the services with expertise in responding to the needs of people who are at the end of life are better placed to act as a resource for young people living in these circumstances.

6.3.2. Palliative and end of life care services

Palliative and end of life care in the UK is provided by a range of health, social care and voluntary sector practitioners working in a variety of organisational settings including acute hospitals, hospices, primary care services and home care providers (Addicott and Ross, 2010). The purpose of this section is to explore how staff working in these settings engage with young people when they have a parent at the end of life, and the extent to which they are able to provide an effective resource to young people living with parental illness.

Whilst the ill parent of each of the young people in the current study was receiving treatment from an end of life care service provider, or multiple providers, young people themselves reported relatively little contact with these services. Five of the ten young people made some reference to services that provide care for their parent in their accounts of everyday

family life. Some had only marginal contact with palliative and end of life care practitioners themselves:

> *I've not really spoke to them unless like I've been up to the hospital, like visited my Mum, and they just don't usually say anything, they just usually smile and say 'Hi'.* (Ellie, 16)

> *I went to visit [Dad] at the hospice, but other than that I've not really had any involvement with any of the services that have been around. I've been quite interested in the occupational therapist's work, because that's something I'm still kind of considering doing, but I haven't had any proper involvement. I've just kind of been there to collect deliveries and not much else.* (Elliot, 18)

Young people who provide a significant amount of practical care for their ill parent are more likely to have been in contact with palliative and end of life care services. Jess has been issued with a card inscribed with the direct telephone numbers of key practitioners involved in her Mum's care:

> Jess: *When I need to, I phone up. Sometimes they can't answer really important questions over the phone cos they're not allowed to. Depends on the questions you ask. Sometimes you just go up [to the hospital] and talk to them*.
>
> Nicola:*And has that been helpful?*
>
> Jess: *They've not helped me but they've helped my Mum - because I try to get her less pain than she's always in*. (Jess, 17)

Jess appears to have used this resource more as a means of accessing support for her Mum than for addressing her own needs; Jess stated that she does not want any support for herself. Jay emphasised that he prefers to rely on friends for support than 'just an official who's doing their job'. He is critical of the home care service providers who have visited his home in the past, but explained that the current care worker is also his Mum's friend:

She's actually my Mum's friend as well, so if she's here and I'm at college, she can speak to her, so it's support from another person. Another carer, they wouldn't even properly speak to you.

(Jay, 17)

Only Lauren reported receiving comprehensive and valued support from palliative and end of life care services. The increased availability and accessibility of practitioners from these services was in direct relation to the escalating care needs of Lauren's Mum; as a consequence of her deteriorating health, the family were receiving home visits from their general practitioner (GP), district nurses, MacMillan nurses, hospice at home volunteers and home care service providers. As the main provider of family care for her Mum, Lauren is more likely to have had direct contact with services herself. Lauren commented:

It's a bad situation, but there's lots of things in place and we could have more if we wanted it...There's always people in and out, and if we ever have a question we can ask them or, like I say, it's very – not smooth – I don't mean smooth, but erm, it's very well-oiled – I can't think of the right terms, but you know what I mean...There's lots of things in place that make it a lot easier for us. (Lauren, 21)

In this extract, Lauren's use of the third person 'we' and 'us' indicates how her support needs are intertwined with those of her Mum, such that when her Mum is being cared for by services, Lauren feels supported in her caring role. However, some practitioners also engage with Lauren directly:

Our GP is very good, really good...she always kind of asks me, 'How are you doing?' kind of thing, you know. 'Yeah, I'm good', and she always asks Mum as well. (Lauren, 21)

Young people's accounts suggest that palliative and end of life care services function as a resource for young people with a parent at the end of life primarily through meeting the needs of the ill parent, enabling young people to gain support as a product of the interdependent

relationship of care they share with their ill parent. When the parent is approaching the end of life, service involvement is likely to increase, potentially bringing young people into closer contact with practitioners in palliative and end of life care. However, there are few examples in the current study of practitioners pro-actively engaging with young people themselves. Previous research suggests that there may be a number of explanations for this (Fearnley, 2010; Sutter and Reid, 2012). For example;

- Palliative and end of life care practitioners prioritise the parent in need of care and do not have the capacity to address the needs of family members.
- Practitioners tend to visit parents at home during the day when young people are at school, college or work, and therefore they have little opportunity to talk with them.
- Practitioners want to avoid causing further distress to parents by drawing attention to the needs of young people in the family.
- Practitioners are aware that the young person's parent does not want them to be informed about the seriousness of their illness.
- Practitioners lack confidence in talking to young people and think that children's services are better placed to address their needs.
- Practitioners are troubled by the prospect of encountering distress in young people, and therefore avoid initiating potentially difficult conversations.

The lack of opportunity for young people to engage with practitioners who are caring for their parent may result in young people feeling excluded from a potential source of support and isolated in their endeavours to keep going in their everyday lives. Luke reflected:

> *I've never done or had anything that's helped. I've just sort of, I suppose, got on with it kind of thing.* (Luke, 18)

When taking into account the lack of engagement with staff in education services, there is a significant risk of young people living with a parent at

the end of life being overlooked, or of being 'hidden in plain view' of services who are in contact with them or their family. This is in spite of a policy framework in end of life care that continues to advocate the importance of addressing the needs of carers, families and those who are important to the dying person (National Palliative and End of Life Care Partnership, 2015).

The need to develop a more holistic approach to the delivery of end of life care services and to consider the ill person in relation to their family and wider networks of support has been highlighted (Broom and Kirkby, 2013; Forbat et al., 2009). In general, the accounts of young people in the current study suggest that palliative and end of life care practitioners currently act as a resource for young people indirectly through the provision of care for their parent. However, young people may want access to information, advice and support for themselves, and people who are approaching the end of life may want services that recognise the significance of their relationships with others. Gandy et al. (2012) offer the scenario of a care worker who provides a meal for an ill parent, but not for their children, as an example of how the lack of a whole family approach may be experienced as a deficit in care when people are approaching the end of life. Further investigation of practitioners' roles and responsibilities with regard to family members may be necessary if the policy intention of more comprehensive support for those who are in need of end of life care is to be realised in practice.

In the following section, I consider an alternative approach to delivering support to young people with a parent at the end of life by exploring young people's use of services that offer opportunities to engage in peer support with others who are living in similar circumstances.

6.3.3. Peer support services

As I explained in Chapter Three (Methodology), two of the young people in the current study were recruited through a Young Carers' Project. The Young Carers' Project is part of a well-established network of support

services in the UK for young people who have been identified as young carers; providing advice, information, practical and emotional support (The Children's Society, 2015).

Ellie and Jess referred to the Young Carers' Project as an important resource in helping them to get on with their everyday lives:

> *I have the Young Carers' worker, she helps...and knowing that I can get a break sometimes and like come to [Young Carers' Worker] or Young Carers' and meet other people, like in just the same situations as me.* (Ellie, 16)

> *When I first met [Young Carers' Worker] I didn't like her, didn't want her involved, but thank God I got involved. She's helped more. She's the only person I can really talk to .* (Jess, 17)

The Young Carers' Project offered support by providing keyworkers to young people who maintained a relationship with them throughout their parent's illness; Ellie and Jess had each had a keyworker for around ten years. Keyworkers acted as someone the young person could talk to, and also provided instrumental support in helping young people access other resources. For example, it was Ellie's keyworker who informed her school about her Mum's illness and triggered a referral to the school counsellor.

As well as providing access to a keyworker, the Young Carers' Project organised group sessions and social activities that enabled young people to meet and talk with others who had also been identified as young carers. Young people found the opportunity to meet with peers living in similar circumstances particularly helpful:

> *Sometimes we're in different situations with different illnesses, like maybe a brother or something, but they've still got illness in the family; like their life is hard and all, because they need to help.* (Ellie, 16)

This form of support may act as an extension to young people's own friendship networks, with the additional assumed advantage that other

young carers do not present the same risk to the young person of becoming distressed, or responding negatively to their family situation. However, the common denominator for young people attending carers' projects is not the everyday experience of living with dying, as young carers may have family members with conditions as diverse as physical disability, mental health issues or chronic illness. As Ellie makes clear, the shared experience is their involvement in providing practical care; 'they need to help'. She explained:

> *People are not in my situation and all that, like they don't know. They just find everything easy and all that. Although when you do go in my situation, it's not easy*. (Ellie, 16)

Jess echoed Ellie's interpretation of living with parental illness as 'not easy':

> *People my age, and my friends and that, they moan about stuff in the house, about their Mum and Dad and all that, but they don't know what I go through. They know what's up with my Mum and that, but they don't see it; they don't do what I need to do.* (Jess, 17)

The need to provide high levels of care labour may be challenging for any family member, but is assumed to be particularly problematic when the direction of care transgresses the normative expectation of parent-child relationships (Clarke and O'Dell, 2013). Clarke and O'Dell describe how the emergence of research on young people as carers was instrumental in bringing to light a previously hidden family trouble; shaping policy and mobilising resources towards alleviating the 'plight' of young carers (2013: 76). However, they contest that the pathologising of young people's involvement in family care through the policy discourse of young carers as 'children in need' is not supported by more positive or nuanced accounts of care between young people and family members (McDonald et al., 2010; Smyth et al., 2011).

Furthermore, the focus on the needs of young carers arguably marginalises the experiences of parents who need care and draws

attention away from the relationships and social circumstances in which care takes place. Newman (2002) offers an alternative perspective to the policy discourse on supporting young carers, proposing that increasing support to parents is a more effective strategy for addressing concerns with the care provided by young people.

As well as disconnecting the needs of parents from those of their children, the identification of young carers as a social category runs the risk of marginalising the experiences of young people who care. Whilst Ellie and Jess allude to feeling set apart from their friends, it is possible that their involvement in the young carers' project reinforces this aspect of their identity and contributes to the sense of being 'othered'. I suggest that in addition to valued support, the young carers' project provides Jess and Ellie with a lens for viewing their experiences of living with parental illness, and a language for talking about their everyday family lives. This may serve to validate a lived experience of difficult circumstances that is troubling for a young person, but it may also shut down the possibility of finding an alternative discourse to that of young people who provide care as 'lost children' (Aldridge and Becker, 1993), and further alienate young people from their peers.

Jamieson and Highet (2013) conclude their study of young people's experiences of loss with the view that 'minimising being troubled includes setting aside negative discourses framing loss as continuing trouble' (2013: 145). I suggest that the social policy discourse on young carers potentially amplifies the experience of living with a parent at the end of life as troubling for young people, even though young carers' projects may provide a valued source of information, advice and support.

There were no instances of young people in the current study referring to more formal sources of peer support other than the two young people who belong to a young carers' project. I had anticipated that some young people may use the internet or other forms of social media as a resource when living with a parent at the end of life. The Maggie's Centres' Trust,

for example, hosts an on-line forum where discussions with peers may take place outside the framework of a young carers' discourse (www.riprap.org.uk). However, only one young person acknowledged using the internet to look up information about his Mum's illness:

> *Erm – yeah. Yeah I did. I just – yeah. I can't really remember what I did but I, yeah, I remember type, I remember doing some, I remember doing something.* (James, 17)

James appeared reluctant to discuss his use of the internet, which is at odds with the contemporary construction of young people as 'a digital generation' (Buckingham and Willett, 2006). It is possible that some young people in the current study have limited access to the internet; studies indicate that both the extent and reasons for internet use vary according to factors such as age, gender and socioeconomic status (Livingstone and Helsper, 2007). The low usage of the internet as a resource in the current study, and James's discomfort at talking about his use of the internet, indicate that more research is needed to understand young people's access to, and attitudes towards, on-line support when they have a parent at the end of life.

This section has explored young people's use of services that offer opportunities for peer support when they are living with parental illness. These services were not widely used by young people in the current study; young people do not appear to seek out support groups or on-line support for themselves. Where young people did access peer support, they reported finding contact with others living in similar circumstances helpful. However, identification with a particular peer group may also exacerbate the sense of being different from other young people. In general, young people's chosen relationships with friends appear to provide more scope for young people to develop a narrative of everyday family life that allows for an alternative to the dominant discourse of their experiences as harmful, and of themselves as damaged by living with parental illness.

In the following section, I further investigate the significance of young people's agency in constructing an account of their experiences of living with a parent at the end of life by examining how young people talk about the future. I explore the notion that in developing an account of the future, young people in the current study draw on both material and symbolic resources to imagine a future self, and that this narrative of a future self supports young people in getting on with their everyday lives in the present.

6.4. THE FUTURE

In her study of children's accounts of family life following parental separation or divorce, Smart (2006) suggests that the construction of a narrative enables children to 'stand outside' of and reflexively evaluate their experiences (2006: 155). She argues that in making sense of their past experiences, children develop the capacity to apply their understanding to future events, such that narratives provide a means of structuring future experiences. The construction of a narrative therefore enables children to exercise agency in developing an account of the self, but also provides a resource for them to draw on to make sense of future events.

In this section, 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 to 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. For example, research on young people who provide care in their everyday family lives suggests that the structuring of young people's future lives is directly linked to the care labour they carry out in the present; in particular, that young people's participation in education and training is negatively influenced by their caring responsibilities, which impacts upon qualifications gained and future employment prospects (Hounsell 2013). Concomitantly, a study by Kloep et al. (2010) of young people's views of their present and future selves suggests that

the assumption of young people who are involved in family care that they will continue to carry out care labour into adulthood impacts on young people's choices and actions in the present. Present and future accounts of the self can therefore be regarded as co-constructive, with each informing and shaping the strategies available to young people in getting on with their everyday lives.

In terms of creating a narrative of the future, young people in the current study differ from many young people who live in families where they may be required to provide care for a family member in that they are aware their parent's prognosis is limited, even if they choose to move in and out of a state of awareness at different times (Copp and Field, 2002). In thinking about their future selves, young people are therefore reaching towards a time when their parent will no longer be with them. The expectation that they will continue to be involved in providing family care in the future can thus be seen as potentially different for this particular group of young people.

I begin this examination of the future in the accounts of young people with a parent at the end of life by exploring the futures young people envisage for themselves. I outline the material and social resources young people anticipate having access to, and consider how an imagined future self may 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.

6.4.1. The young person's future self

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

> *I want to move away from [home town] and I want to do a job like in advertising or something.* (Ellie, 16)

> *Going to college and then hopefully maybe going on to uni or getting a job and moving out, having a family and everything of my own at some point.* (Dan, 16)

> *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 the notion that they may need to continue to support family members. James acknowledged that his plans for the future were being formed in the context of his Mum's illness:

> *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 the on-going needs of family members were taken into account, the potential impact on young people's future lives was navigated around. For example, although Jess intends to take responsibility for her siblings in the future, she stated:

> *I'll still be able to do the things I want to do. I still can go to college. I don't see any point in putting that off...I'll just get on and do what I need to do.* (Jess, 17)

Young people who had returned home to be there for family members presented this decision as temporary. For example, in Chapter Five (section 5.3.2.), I discussed how Lauren and Elliot had suspended their plans to live away from home, but intended to return to university after their parent's death:

> *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 is careful to take the needs of family members into consideration when thinking about his future. In his account, he muses on how he will balance his wish to get on with his own life with the likelihood that his Mum will continue to need support following his Dad's death:

> *That's the thing, depending on how it's timed, 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)

Even when anticipating the needs of family members, young people are motivated to continue pursuing their own plans for the future. Furthermore, in basing their future narrative on the acquisition of material and social resources such as a job, an apprenticeship, their own home or a car, young people gain something to work towards, giving meaning and a sense of purpose to their everyday lives beyond the experience of parental illness. The awareness that their family situation is going to change in the foreseeable future appears to enable young people to keep sight of their aspirations for their future self. Therefore, whilst living with a parent at the end of life underpins the uncertainty of the new normal in young people's everyday lives in the present, it paradoxically reinforces the certainty of change in the future.

Some researchers have drawn on Bury's (1982) notion of biographical disruption to explore the experience of chronic or life-threatening illness (Trusson et al., 2016; Wilson, 2007). The model of illness as biographical disruption suggests that the experience of illness disrupts taken for granted assumptions and routine behaviours, threatens the individual's sense of themselves and their relationships to others, and necessitates the mobilisation of resources in response to change. Research on family carers from the perspective of biographical disruption is limited, but Greenwood and Mackenzie's (2010) meta-synthesis of qualitative studies found evidence of biographical disruption in family carers of stroke survivors.

I considered the relevance of biographical disruption as a framework for understanding the experiences of young people in the current study; as I suggest in previous chapters, taken for granted assumptions about family members being there for young people, and the moral imperative for families to put the needs of children first do appear to be disrupted when a parent is approaching the end of life. Furthermore, the everyday routines and practices of family members often have to adapt to incorporate change and uncertainty in young people's everyday lives. Young people mobilise a range of resources in order to keep going, for example; finding ways to reinforce the sense of belonging to a functioning family, giving care to family members, and making careful use of their relationships with friends.

However, young people's accounts of the future do not appear to support the interpretation that a young person's biography and self-identity are fundamentally altered by the experience of living with a parent at the end of life. Although young people are facing considerable disruption and significant loss in the future, their sense of their own future appears to retain a coherence and purpose based on normative associations of youth as time for moving away from the immediate family environment. Even young people who have adopted the self-identity of a young carer appear to have done so temporarily for the duration of their parent's illness, and

do not envisage a more permanent re-shaping of their identity in relation to others.

Rather than representing a fundamental disruption to the life of a young person, the experience of living with parental illness appeared to constitute an interruption of an ongoing biographical narrative for young people in the current study. The anticipated trajectory of the young person's life appeared to remain a constant in their accounts of everyday life, and young people generally expected to reconnect with their projected future following their parent's death. The dimension of biographical interruption/biographical continuity may therefore offer a more useful construct for understanding the experiences of young people with a parent at the end of life than that of biographical disruption. The accounts of young people in the current study suggest that whilst young people may suspend their future plans while they are living with parental illness, they anticipate continuing to move towards their narrative of a future self beyond the death of their parent.

Overall, young people's narratives of the self in the present and in the future can be seen as closely woven threads in their accounts of everyday family life, and often intertwine to add meaning and purpose to the experience of living with parental 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)

> *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)

The troubles Dan is experiencing in the present strengthen his resolve to succeed in what he wants to achieve in the future. Luke seeks a future for himself where he goes 'from strength to strength', and this gives him the resolve to focus on his own needs in the present. Young people therefore draw on their narrative of the future to make sense of their lives in the present, whilst their present narrative provides a means of structuring future experiences.

One account that provided an exception to the affirmative relationship between the present and the future in young people's narratives of living with parental illness was that of Jay. Jay has experienced a number of challenging events over the course of his life, and as a consequence he reports feeling that he has little in the way of resources with which to build a positive narrative of the 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, and presented his future as a series of questions:

> *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 experience of parental illness and the associated ambiguity and uncertainty of his everyday life appears to have cast a shadow over his future, preventing him from seeing a life for himself beyond his Mum's death. A future without his Mum is hard for Jay to contemplate:

> *I want to get good grades and I want to go to university and I want to see myself with a good job. I want a family myself, but I also want to see my Mum - but it kind of seems quite hard to get, I guess...I kind of feel that I know I'm not going to get good grades. I kind of already*

feel that, and I also feel that things that I want to do, I don't think I'll be able to do. (Jay, 17)

Here, Jay's uncertainty about his future is not only linked to his Mum's prognosis, but also to the difficulties he has experienced since starting his education. In order to protect Jay's identity I will not provide any further details here, but Jay is aware that as a consequence of the challenges he has faced, he is unlikely to achieve the qualifications he needs to gain access to the future he would like.

Jay's account of his life to date provides him with little sense of how he might structure future events to influence the course of his narrative, and he is unable to construct a coherent future narrative to help him make sense of the present, leaving him with a series of unanswerable questions. Reflecting on Jay's experience, I suggest that young people who lack the material and social resources to develop a 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 at the end of life.

In the following section, I continue this exploration of young people's future narratives by considering in more detail the significance of the young person's ill parent as they appear in young people's accounts of their lives in the future.

6.4.2. The present-absent parent

In Chapter Four, I described how living with a parent who is not going to be there in the foreseeable future troubles the meaning and everyday experience of family for young people when they have a parent at the end of life. For some young people, the sense of family is not only troubled in the present, but also in their narrative of the future. For example, when asked about the 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 continuity of family as a narrative transmitted across generations is troubled by the anticipated death of his Mum. Dan imagines that through her absence, his Mum will continue to have a tangible effect on him and on his family in the future, thus attributing her with a presence in his everyday life that extends beyond her death. This suggests that the process of 'continuing bonds' (Klass et al., 1996) and in particular, the relational experience of the 'absence-presence' of the deceased (Maddrell, 2013), may begin prior to bereavement in response to living with dying.

It appears that young people envisage their parent as absent when they are 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 thus appears to function as a form of rehearsal for a future in which the parent will no longer be there, and enables the young person to begin the process of making sense of anticipated changes in their own lives. Elliot described how the notion of his Dad's absence has influenced how he feels about the future:

> *It has limited what I want to do with my life, and all the things I want to do that didn't involve them. Often when I think about those plans, as I would every so often anyway, I do think, 'Oh well, I can't*

really just get back from there and then tell him how it was any more, cos he won't be around'. (Elliot, 18)

The practice of imagining their parent as absent when they are still a presence in the young person's everyday life 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 (Maddrell, 2013). I suggest that the *present-absent* parent functions as a symbolic resource for young people who are living with parental illness, enabling them to re-evaluate the meaning of their everyday lives as they move towards the future with a parent who is at the end of life. For Jay, the difficulty of contemplating his Mum's absence appeared to compound his trouble with constructing a narrative of his own future:

I prefer not to think of the future cos I know that - my Mum's health is really bad. (Jay, 17)

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

Finally in this section, I consider how a young person's narrative of the future is sometimes augmented by the suggestion that they are fulfilling their ill parent's wishes by seeking a 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 notion that they are responding to their dying parent's request lends support to a young person's decision-making with regard to the future. Lauren explained her decision to return to university to complete her final year as follows:

> *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)

These quotes suggest that for some young people, the reassurance that they have their parent's endorsement of their future plans enables them to get on with their lives. Ellie's and Lauren's accounts provide some indication of the emotional labour undertaken by their mothers in continuing to offer encouragement and support as they approach the end of life. Previous 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 enable their daughters to develop a moral tale, in which Ellie and Lauren are 'doing the right thing' by shifting attention to their own futures.

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

> *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 commemorate his Dad by doing an activity they enjoyed together demonstrates the emergence of strategies to maintain continuing bonds with an ill parent prior to their absence through death. These accounts illustrate how young people begin to experiment with notions of parental absence and presence, moving imaginatively between the two states and blurring the boundaries such that they are less absolute categories and more positions on a continuum. It is possible that the practice of re-locating their parent along this continuum whilst they are living with parental illness may facilitate young people getting on with their everyday lives in the present, and may help to develop a moral framework for structuring their account of the future.

6.5. CONCLUSION

In this chapter, I have examined the resources young people draw on outside of the family when they are living with a parent at the end of life. Whilst all families face troubles, including dying and death (Ribbens McCarthy et al., 2013), the extent to which 'normal' troubles are experienced as extraordinary or overwhelming may depend on the availability of social and material resources with which to ameliorate how troubles are encountered in everyday family lives (MacDonald & Shildrick, 2013; Evans, 2013).

I have focussed on the material and social resources available to young people when they have a parent at the end of life, and have identified friends as the resource outside of the family most young people prefer to draw on. Young people make careful use of close friendships as a source of emotional support, but also value spending time with their friends as a distraction from living with parental illness, and for the pleasure gained from shared interests and activities.

In terms of access to services, young people are most likely to be offered support via their school or college. However, education providers do not necessarily know when young people are experiencing troubles in their everyday family lives, and their capacity to respond may be limited by the

lack of availability of appropriate services. Young people in the current study reported mixed responses to school-based counselling and pastoral support, suggesting that there is scope for improvement in how those services most likely to be in contact with young people recognise and respond to young people who are living with parental illness.

Most young people appear to have had little contact with palliative and end of life care services, unless they had been identified as the main carer for their parent and their parent was very near to the end of life. Practitioners in these services may have little opportunity for direct contact with young people, but the lack of a holistic approach to the care of people at the end of life and *those who are important to them* is counter to end of life care policy, and points to the need for more consideration of how this policy aspiration can be translated in to practice. Meanwhile, it appears that young people in families with a parent at the end of life risk falling into the gap between generalist services, where staff are less well equipped to address the sensitive issue of dying and death, and specialist services, where staff are less well positioned to provide direct support to young people. As a consequence, it is possible that many young people are being excluded from any offer of support when they are living with a parent who is dying.

Peer support of the type offered by young carers' projects was found to be helpful by the two young people who had access to it, but is framed by a policy discourse that may perpetuate a narrative of living with parental illness as one of harm whilst ignoring the diversity of individual experiences and impacts it encompasses. As Ribbens McCarthy et al. (2013a) write 'naming harm easily slides into the presumption of damage' (2013a: 11), and forfeits the recognition of young people's agency, resistance and active utilisation of available resources in responding to difficult circumstances.

For the majority of young people in the current study, all of whom are aware that their parent's prognosis is limited, one resource that does

appear to be available to them is the capacity to imagine a future for themselves beyond the experience of living with parental illness. Young people's narratives of the future reflect an awareness that they will not be living in difficult circumstances indefinitely, even though embracing the potential for change in their own lives depends on an acknowledgement that the future contains the absence of their parent. However, young people need access to adequate material and social resources with which to develop a future self before they can draw on this as a resource. 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.

CHAPTER SEVEN: CONCLUSION

Family remains a site of major significance for all those involved in end of life care. Researchers, policy makers and practitioners have continued to attest the importance of family members in providing care at the end of life. Yet young people's experiences of family life and of care in families when someone is dying have largely been overlooked. This appears particularly paradoxical given the centrality of children and young people in normative discourses and social narratives of family life in the UK. This exploratory study provides new insight into young people's experiences of living with a parent at the end of life and adds to the literature on everyday family lives, particularly in the context of end of life care.

I selected an in-depth, qualitative methodology to address the gap in current knowledge and understanding of the prospective experiences of young people living with a parent at the end of life. Two key aspects of the study design in particular enhanced the potential for generating new insights. First, the study applied a sociological lens to explore the experiences of young people with a parent at the end of life. A sociologically-informed understanding of 'family' and of 'care' was employed to interrogate young people's experiences of family care when a parent is dying. This is in contrast to existing health sciences and social policy research, where there has been limited theoretical explication of the concept of family care to date. Therefore, the notion of care as a burden to be shouldered by an adult family member has tended to dominate this field.

Second, I adopted a multiple perspectives approach to focus on the views of young people themselves whilst taking into consideration the familial and wider social narratives that shape young people's accounts. This methodology reflected my understanding of young people as agentic subjects engaged in making sense of their own experiences, whilst the inclusion of significant others brought into the frame factors that influence and constrain young people's meaning-making activity. The

choice of a multiple perspectives methodology differed from previous research in this area; existing studies (e.g. Kühne et al., 2012; Macdonald et al., 2016) have tended to focus on intrapersonal factors related to the young person or their parent and to be framed by the presumption that living with advanced parental illness incurs damage.

The research literature to date has therefore either rendered young people living with advanced parental illness invisible, or offered little scope to develop an alternative narrative to the 'harm story' (Ribbens McCarthy et al, 2103: 11) associated with facing parental bereavement at what is normatively considered to be an inappropriately young age. In contrast, listening to the voices of young people in the current study and being attentive to how they positioned themselves in their narratives of everyday family life opened up the possibility of acknowledging alternative discourses, through which young people endeavoured to minimise or deflect 'the trouble loss brings' (Jamieson and Highet, 2013: 135).

In the conclusion to this thesis, I summarise the key and innovative findings from my study with reference to the study questions outlined in Chapter Three (p. 66). I indicate where there may be potential for further research in response to questions raised by the study, and I suggest points that may merit consideration by practitioners working with young people who are living with a parent at the end of life.

7.1. YOUNG PEOPLE'S EXPERIENCES OF FAMILY

How do young people experience everyday family life when they are living with a parent at the end of life?

The notion of 'closeness' emerged as significant to the meaning of family for young people living with advanced parental illness. Spatial and emotional definitions of closeness converged in young people's understanding that the proper way to do family when a parent is at the end of life is through the provision of care. Young people valued relatives

being there to care for their immediate family, whether they gave practical assistance or offered emotional support and reassurance from a distance. In particular, young people were highly sensitised to the moral significance of the actions of family members in offering or withholding care; those who failed to rally round troubled young people's sense of what they could legitimately expect of family members and disturbed the meaning of family as belonging to a cohesive unit.

The experience of closeness and belonging may be particularly important for young people whose parent will not be there for them in the near future. When a young person's sense of family is threatened by the loss of a significant member, the need to marshal resources and bolster the strength of family bonds may become more urgent, and therefore more endangered by individuals who are perceived as not *being there*. The importance of presence and absence is one salient aspect of young people's experiences of family life this study has revealed.

A second feature of young people's family lives that has received little attention to date is the length of time young people have been living with a life-limiting parental illness. Many young people in the study had a parent who had been ill for as long as they could remember, therefore the uncertainty and change associated with parental illness had become a *new normal*; a routine part of everyday family life. Young people recognised there was little that could be done to alter their parent's prognosis and talked about needing to get on with their lives. Certain practices emerged as helpful in supporting young people in *keeping going* or *getting on with it*; these will be summarised in the following section.

The on-going sense of uncertainty and change at the core of family life for young people with a parent at the end of life is less evident in studies involving young people who have been bereaved (e.g. Fearnley, 2010). It is possible that young people who are responding to a significant loss may be less likely to reflect on the ambivalence and ambiguity they have experienced over many years. Carrying out a prospective study of young

people's family lives while they are living with a parent at the end of life was challenging at times, particularly with regard to study recruitment. Nevertheless, this approach generated significant insights and supported a new contribution to current knowledge and understanding of young people's experiences of living with dying.

7.2. GETTING ON WITH IT

What practices and processes help or hinder young people in these circumstances in getting by?

Young people's strategies for getting on with their lives can be seen as a response to the critical features of family life with a parent who is dying described in the previous section; the importance of presence and absence to the meaning of family for young people, and the normalised experience of uncertainty and change. In this context, practices that emphasised and enhanced the sense of presence, stability and belonging took on a new significance in young people's everyday lives.

Maintaining everyday routines built around attendance at school or college provided a sense of continuity and the prospect of time away from the family environment to spend with friends. Friends were the most important source of support to young people; almost all young people had friends they confided in about their experience of life-limiting parental illness. However, friendships were also a source of pleasure, and it need not be assumed that friends were important solely or mainly for 'therapeutic' reasons. The tendency to view every aspect of young people's lives through the lens of parental illness has contributed to the 'othering' of young people when they have a parent at the end of life. The positioning of young people living in these circumstances as extraordinary further pathologises the experience of living with dying and limits the potential to recognise alternative narratives. In avoiding the presumption of damage, this study offers a new interpretation of young

people's experiences, which emphasises young people's agency in finding ways of living with uncertainty and change.

This approach does not deny that the experience of living with a parent at the end of life challenges the continuity of family and is troubling for young people. However, it does foreground the view that all families experience troubles, and that death is (at least statistically) a 'normal' part of family life (Ribbens McCarthy, 2007). One question therefore concerned the extent to which the life-limiting illness of a parent represented 'a disruption of a *different* kind' (Ribbens McCarthy, 2007: 288). The accounts of young people in the current study suggest that it is the ontological insecurity associated with the imminent loss of a parent that is particularly significant for young people with a parent at the end of life. Strategies for *keeping going* in their everyday lives were often aimed at consolidating the sense of togetherness and belonging provided by family to counter the disruption associated with living with dying on both a practical and an existential level. The notion of presence and of being there to support other family members was also important to young people in making sense of their own lives, and was enacted through young people's involvement in care.

7.3. EXPERIENCES OF CARE

How do young people experience care in the context of a family with a parent at the end of life?

Previous research on young people's involvement in family care has tended to apply the social policy framework of 'young carers'. This perspective has been criticised for its emphasis on the negative outcomes of providing care for young people and for denigrating the ability of parents with a disability or a long-term condition to care for their children. In contrast, the sociological perspective adopted in the current study opened up new lines of enquiry with regard to family care at the end of life by approaching care as a significant expression of the relational

identities of family members, including young people. Young people in the current study demonstrated a strong commitment to caring for family members based on an understanding of family expressed in terms of closeness, reciprocity and being there.

The study indicated that young people's involvement in the physical activities of care when a parent is at the end of life varied considerably depending on the wider resources available to the family. However, the physical practice of *caring for* a parent was not the most troubling aspect of living with advanced parental illness. Young people were more troubled by the emotional practice of *caring about*; the watching, waiting and worrying about their parent that accompanied the everyday routines and practices of family life. It was apparent from young people's accounts that the 'little fragments of daily life' that constitute family according to Morgan (1996: 89) carry emotional weight, such that physical and emotional practices of care were coexistent and mutually reinforcing. An analysis of young people's caring activities or of family practices when a parent is at the end of life that privileges measurable, observable actions over less tangible emotions therefore cannot adequately capture the quality of young people's experiences.

Of particular significance to young people in the current study was the shift that occurs in families with a parent at the end of life away from the moral imperative to put the needs of children first towards a new, competing imperative to care for the dying. Although they may have continued to care for their children, parents at the end of life required more care from family members as their illness progressed. The discourse of a good death ensured that family members were 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 members to meet their needs was undermined as a consequence. This potentially reinforced the 'disruption of a *different* kind' based on unsettling experiences of absence for young people with a parent who is dying. The indication of a shift in the moral dynamics of

family when a parent is at the end of life 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 can be overridden without sustaining the loss of a moral reputation, at least for adults in the family.

The findings of the current study suggested that the shift in the moral compass of family may take place over a number of years, during which time young people become accustomed to the new normal of living with parental illness and find ways of getting on with their lives. Recognising some responsibility for caring for their parent, other family members and themselves was often part of the strategy for keeping going. This supports previous research, in which involvement in care was one means by which young people could exercise agency in a situation that was characterised by uncertainty and a lack of control (Backett-Milburn et al, 2008). Furthermore, caring for others did not exclude caring for the self, since the relational identities and interdependence of family members meant that these spheres of activity often overlapped to create a form of *caring for self-and-others.* Problematising young people's involvement in care and seeking to remove young people's caring responsibilities may therefore be counter-productive, as well as being impracticable. In addition, I suggest that whilst living with dying undoubtedly troubled young people at times, there was also a mundanity to their experiences that is not acknowledged in the literature, in that young people found ways to accommodate their experiences in and through the everyday routines and practices of family life.

7.4. YOUNG PEOPLE'S SENSE OF THEIR OWN LIVES

How do young people who are living with a parent at the end of life make sense of this experience in relation to their own lives?

The 'everydayness' of living with dying raised a further question posed by Ribbens McCarthy et al. (2013) with regard to when the 'normality' of an

experience and the continuity of everyday life should be emphasised, and when a line should be drawn around experiences that may require intervention. This study has contributed to this debate by exploring how young people themselves make sense of living with advanced parental illness, and how notions of continuity and crisis are reflected in their accounts of everyday family life.

In general, young people in the current study reported few examples of services intervening to support them in 'coping' with parental illness. Instead, service providers who were in regular contact with young people often appeared to be reluctant to approach them to talk about living with a parent at the end of life. This 'conspiracy of silence' (Fearnley, 2010: 455) has been noted by other researchers, and needs to be addressed if young people who would like the support of services are going to be able to access help. However, not all young people wanted or felt they required the intervention of services to enable them to make sense of their lives.

As I have discussed, when they wanted to talk about their experiences of parental illness outside of the family, young people expressed a preference for approaching friends. Nevertheless, young people were *care-full* about who they spoke to, when and how, and were wary of the potential to cause distress by raising the sensitive subject of living with dying. Young people's discomfort reflects a broader societal unease at the mention of dying and death. The Dying Matters coalition are attempting to overcome the taboo surrounding death, launching initiatives such as Dying Awareness Week and The Big Conversation[11], which endeavours to open up discussion on the subject of death in local communities, workplaces and faith organisations. However, more needs to be done to create spaces in schools and colleges where young people can feel comfortable to talk with their friends about living with dying, should they wish to do so.

[11] See http://www.dyingmatters.org/BigConversation for more information

The study found that, in contrast with other research studies in this area, young people did not necessarily want 'not just the truth, but the whole truth' (Chowns, 2013: 28) about their parent's illness. Putting aside the issue of what might constitute 'the truth' in the nebulous terrain of life-limiting illness trajectories and end of life prognoses, young people in the current study demonstrated an astute awareness of what they wanted to know, and when they knew enough to meet their current needs. I suggest that one reason for this difference in findings may be that previous studies have mainly been conducted with young people whose parent has already died. In these circumstances, young people may have been drawing on the benefits of hindsight to convey a sense of 'if only I had known then what I know now'.

The uncertainty surrounding the end of life and the event of death itself underpinned the accounts of young people in the study, but I suggest that it is not possible to provide 'knowledge' of how a parent's death may be experienced by a young person due to the number of variables in each family's specific set of circumstances. It is therefore difficult to determine with certainty what might constitute useful information for a young person with a parent at the end of life, and attempting to provide 'the whole truth' in this context may confront them with information that is inaccurate, unhelpful, or that they are not ready to receive. Instead, I suggest that parents and practitioners need to open up a channel of communication with a young person and to make clear their availability to offer 'truthful' responses and accurate information as far as possible, whilst respecting the young person's agency in deciding what they want to know and when.

A further contribution this study has made to understanding how young people make sense of their experience of living with a parent at the end of life is to highlight the potential for the future to act as a resource for young people in getting on with their lives. Most young people in the study were able to articulate a future life for themselves and to interpret their everyday experiences of advanced parental illness as transient, and

as an interruption to an on-going biographical narrative. The inclusion of time as a relevant dimension for understanding young people's everyday lives was particularly significant for a study that took place in the context of end of life care. It was identified that young people's experiences of caring for a family member at the end of life potentially differed from those of other young people involved in family care due to the time-limited nature of their caring responsibilities. Young people in the study were aware of their parent's prognosis, and therefore understood that their future lives were not bounded by their parent's on-going need for care.

Some previous studies have referred to living with a parent at the end of life as a period of pre-bereavement, with the implication that young people predominantly understand their everyday lives in terms of anticipating their parent's death. I found that, whilst young people were able to recognise and acknowledge their parent's absence in the future, most maintained a consistent narrative of their own lives alongside the expectation of loss. Young people exercised agency in constructing a narrative of the future and in doing so, were able to give meaning to their lives in the present and to *keep going* in spite of the challenges of living with dying. However, access to an adequate level of social and material resources is necessary for the construction of a future narrative that is robust enough to serve the purpose of helping young people to make sense of their experiences in the present.

7.5. FAMILIAL AND SOCIAL NARRATIVES OF LIVING WITH DYING

To what extent are young people's accounts of living with a parent at the end of life influenced by familial and wider social narratives in the context of end of life care?

The meaning of family for young people expressed in terms of closeness, cohesion and care was evident in the narratives of family members

interviewed for the study, and reflected a shared sense of the importance of family pulling together to support a parent at the end of life. Nevertheless, there were notable differences in how young people and parents in particular interpreted this narrative of family life. Whilst parents emphasised the importance of being there for their children, many young people reflected that their parents were not always able to be there for them due to the effects of parental illness. The multiple perspectives approach applied in this study therefore supported a new interpretation of family life at the end of life by drawing attention to the gap between young people's and parents' experiences. I have suggested that this is underpinned by a shift in the moral imperative for family to care for young people towards caring for the dying; a moral tale of family that has not previously been told in the research on family or on end of life care.

I have drawn attention to the influence of the social discourse of a good death in relation to the moral expectation conferred on family members to meet the needs of the dying individual. I have argued that more emphasis needs to be placed on the relational and often lengthy experience of dying in families where someone is at the end of life and on factors that may help to promote *a good dying* for all family members. Current discourses in end of life care emphasise the importance of open communication between family members, including young people, with regard to the diagnosis, treatment and prognosis of a family member with a life-limiting illness. However, this approach was not unequivocally supported by young people in the current study. The study therefore highlights a wider debate concerning the extent to which the discourses that frame individual and institutional responses to living with a parent at the end of life may lead to interventions experienced as helpful, or may hinder young people living in these circumstances (Ribbens McCarthy et al., 2013). Contrary to previous research, the current study suggests that young people's agency is a more important factor than openness in

determining what constitutes good communication with young people when a parent is dying.

I have also interrogated the discourse on young carers that informs social policy and practice with regard to young people who provide care for a family member. The accounts of young people in the current study suggested that identifying as a young carer may confer a sense of purpose and belonging on some young people. However, it may also serve to marginalise their experiences of family life and contribute to a sense of ambivalence; since the troubling of young people's care-giving conflicts with the notion of family care as an expression of the closeness and cohesion of family members. The uncritical application of broader social discourses of family care at the end of life to young people's everyday experiences of living with a parent at the end of life should therefore be resisted. For those who are working with young people living with advanced parental illness as researchers or practitioners, it is important to reflect on the underlying assumptions that inform our approach and to recognise the potential for young people to develop their own narratives and sets of meanings with which to frame their experiences of everyday family life when a parent is dying.

In the following sections, I suggest some potential areas for future research based on the experiences of young people in the current study and offer some reflections on the everyday lives of young people with a parent at the end of life that may be of interest to practitioners who are contact with young people living in these circumstances.

7.6. SUGGESTIONS FOR FURTHER RESEARCH

- Policy and practice in end of life care may benefit from adopting a more relational view of the end of life and focussing on living well with dying, rather than on a good death. Further research with people who are dying, family members, practitioners and the wider community could help to develop an understanding of what constitutes a good dying from the perspective of all those involved.

- The sensitivities that surround discussions of dying and death in the UK appear to be amplified by the prospect of talking with young people; consequently, young people have few opportunities to explore their understanding and experiences of dying and death in their everyday lives. Further research may help to establish the feasibility of opening up spaces for young people to reflect on dying and death, particularly with their friends and peer relations. One example of this approach can be found in the work of Coombs (2014), who set up focus groups in a school for young people to explore these topics.
- As well as opening up physical spaces for young people to talk about dying and death, there is potential for virtual spaces to be created through the use of social media. Young people's use of social media in relation to exploring experiences of living with dying is currently poorly understood. Further research may help to determine what virtual support young people currently access, and what additional resources might be useful to young people who are living with a parent at the end of life.
- The experiences of young people in the current study suggest that young people receive little in the way of support from services when they have a parent who is dying. Neither young people's services, such as schools and colleges, nor end of life care services appeared to adopt a consistent approach in offering support to young people. Further research may help to understand more about why practitioners in these settings find it difficult to approach young people, and what support they may need to be more proactive.

7.7. RELEVANT POINTS FOR PRACTITIONERS

- It may be helpful for practitioners who have the skills and confidence to talk about dying and death to young people to identify opportunities to do so. Young people do not always want

to talk to practitioners about their experiences, but may appreciate knowing who they can talk to if they wish to.

- At the same time, there is a need to be sensitive to *how* we talk to young people about their experiences of living with dying. It appears important that in opening up a conversation, practitioners do not detract from a young person's ability to determine what they want to know and when.
- There is a need to recognise the whole family in assessing the provision of family care at the end of life, including any young people. Even family members who are not co-resident or do not appear to be doing a lot of practical caring activities may be offering significant amount of emotional care to a person at the end of life or other family members.
- It may be helpful to approach the meaning and practice of end of life care in young people's everyday lives with sensitivity and to recognise that it may be important for young people to determine how much involvement in care is too much for them.
- In considering the impact of living with a parent at the end of life on a young person, it may be helpful to avoid making an assumption of harm, and 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 future narrative that may help to ameliorate the effects of living with dying in the present.

This study has applied a sociological approach to shed new light on the family lives of young people with a parent at the end of life. In doing so, it affirms the on-going significance of family to all those involved when someone is dying. The study has given a voice to the experiences of young people, who have largely been overlooked by studies of family care at the end of life to date and often continue to be silenced by the lack of available support. Without listening to young people's accounts, there is little prospect of improving the way in which this particular set of difficult

circumstances is understood. Nevertheless, what has remained with me some time after listening to the young people in this study is the sense of self determination and resourcefulness young people bring to their everyday lives in changing and challenging circumstances. End of life experiences and broader understandings of family life can only be enhanced by attending to what these young people have to say.

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APPENDIX 1: CONSULTATION MEETING WITH YOUNG CARERS

This consultation meeting took place on 9th April, 2013 at an activity day for young carers organised by a local young carers' project. A total of 5 young people were present, 4 girls and 1 boy, ranging in age from 9 to 13. One person had previous experience of meeting with a researcher to talk about being a young carer. All said that they 'wouldn't mind' participating in a research project. One commented:

> *'I think it's important for people to know what it's like for us...to hear our voices'.*

All agreed that they would prefer to meet with a researcher individually, rather than in a group. One said that she would prefer to be interviewed at home; 3 said that they would prefer to meet somewhere outside of the home, for example in a local library:

> *'I wouldn't want my mum to hear what I was saying'.*

All expressed a preference for face-to-face interviews over other methods of data collection; e.g. questionnaires, use of cameras / video recorders, diaries etc.:

> *'You need to see how the person reacts to what you're saying – erm - if they're shocked or anything'.*

Two young people said that they '*wouldn't mind*' using drawing to describe their experiences; one explained, *'because that's what I'm good at'.* The other young person added, *'but I find it easier to use words'.*

We talked about ways to make young people feel comfortable during a face-to-face interview. There was strong concurrence with one young person's response:

'You need to get to know them first...so they know what you're about...what it's for'.

Providing clear information about the aims and the process of the interview in advance was regarded as important, but most of all, young carers stressed the need to establish a rapport before commencing with the interview, *'taking part in some activities together or something'.*

All of the young people expressed concerns in response to a question about tape-recording interviews. One young person said, *'it would feel more like being interrogated'*, adding that she may say something that would incriminate herself or other family members, and that a tape-recording may be used as '*evidence*'. Another young person was worried about where a tape-recording might end up:

'It could be on the telly or anything'.

We discussed the reasons for recording interviews and the need to be explicit about confidentiality and to reassure young people that there are no right or wrong answers to questions. We also discussed the need to stress what will happen to any tape-recordings, transcripts or other data associated with the research project. Other suggestions young people had for making the process of tape-recording more acceptable were:

- to allow the young person to tape the interviewer first in order to get used to the process
- to allow the young person to decide when to turn the tape recorder on and off

Finally, we talked about the process of providing feedback to young people on the research. All felt that they would like verbal feedback rather than a written report; one commented that she would like it sending to her on a tape. One young person said that she would like feedback on how other people, particularly other young carers, had responded to the research.

APPENDIX 2: PARTICIPANT INFORMATION (>16 YEARS)

Living with a parent who has a serious illness

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

I would like to invite you to take part in a research study. Before you decide whether you would like to take part, I would like you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask me if there is anything that is not clear or if you would like more information. My contact details are on the back of this sheet.

What is the purpose of the study?
We know that families can offer reassurance, comfort and care for people when they have a serious illness. Researchers have looked at the roles, responsibilities and experiences of family members when someone is seriously ill, but so far, this research has concentrated on adults in the family. We want to find out how young people experience family life when a parent has a serious illness, and to understand more about their role within the family during this time. We would also like to explore how family life changes for young people when a parent has a serious illness, and how they see their future.

Why have I been invited?
You have been chosen because you have a parent with a serious illness who is not going to get better. I would also like to invite you to suggest up to two more people in your family who might be willing to take part in the study; for example, a parent, a sibling, a grandparent or someone else who is important to you. This will help me to understand more about your family, but if you do not want anyone else to take part, that is fine.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form at the start of the study. If you do decide to take part you are still free to withdraw at any time and without giving a reason. None of the services your family receives will be affected by whether or not you take part in the study. If you do decide to withdraw from the study then the information collected so far cannot be erased and this information may still be used in the study analysis.

What will happen to me if I take part?
You will be invited to an interview, either in your home, or at another location – whichever you prefer. I will ask you some questions and talk about your family with you. There will be time for you to say anything you think is important that you have not been asked. The interview will take approximately one hour. If you are in agreement, I would like to record the interview using a voice recorder.

Expenses and payments
You will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?
The experience of illness is often a cause of anxiety for families. There is a possibility that the interviews will touch on upsetting topics. However, you will not be under any pressure to answer questions or talk about topics that you prefer not to discuss. The interviews will focus on your experience of family life and what is important to you about your family.

What are the possible benefits of taking part?
Some people find it helpful to talk to somebody neutral during times of change. Sometimes research interviews help people to get their thoughts and ideas clear, which can help when they need to talk to people who provide services. We cannot promise the study will help you but the information we get from this study may help to improve the support provided to young people when a parent has a serious illness in the future.

What if there is a problem?
If you have a concern about any aspect of this study, please speak to me and I will do my best to answer your questions. Alternatively, you can contact my supervisor, Dr Kathryn Almack. Our contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints. Details can be obtained from your health service provider.

Will my taking part in this study be kept confidential?
If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. It may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information which leaves the research unit will have names and addresses removed so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for up to 1 year after the end of the study so that I can contact you about the findings of the study if you have requested this. All other research data will be kept securely for 7 years. After this time the data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain confidentiality. Only members of the research team will have access to personal data.

Anything you say during the interview will be treated as confidential unless you reveal something which indicates the likelihood of harm to yourself or others. In that case, I may need to raise the matter with the relevant people or agencies.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of this study will be written up as part of a thesis for a higher degree at the University of Nottingham and may be made more widely available through journal publications and conference presentations. You and your family members will not be identified in any report or publication resulting from the research. We will send you a summary of the report at the end of the study if you would like one.

Who is organising and funding the research?
This study is being carried out by a researcher from the School of Nursing and the School of Sociology and Social Policy at the University of Nottingham and is being funded by the University of Nottingham.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by Derby Research Ethics Committee.

Further Information and contact details:

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APPENDIX 3: PARTICIPANT INFORMATION (<16 YEARS)

Living with a parent who has a serious illness

- Are you age 13—18?
- Do you have a parent with a serious illness who is not going to get better?
- Could you help us to find out more about young people's experiences of family life when a parent has a serious illness?



I am inviting you to take part in a research study.

My name is Nicola Turner

I work at the University of Nottingham

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Please take time to read this leaflet carefully and discuss it with family and friends if you wish.

You can ask me if there is anything that is not clear or if you would like more information — My contact details are on the back of this leaflet.

What is the research about?

When a parent is seriously ill, families may have to change the way they do things. Family life may feel different for young people as a result. If we can understand more about these changes and how they affect young people, it may be possible to help other young people when they have a parent who is seriously ill in the future.

I would like to talk to you about your family and your experience of family life. I would also like to ask you if there are other people in your family who you think I should talk to. You will be invited to suggest up to two people who are important to you. They will be given information about the study and invited to take part. This will help me to understand more about your family. If you do not want anyone else to take part, that is fine.

Why have I been asked?

You have been asked because your worker knows that you have a parent with a serious illness who is not going to get better.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this leaflet to keep and you and your parent will be asked to sign a form to give your permission to take part.

If you change your mind, you can stop taking part at any time and you do not have to give a reason.

None of the services you or your family receive will be affected by whether or not you decide to take part.

What will I have to do?

We will meet at a time and place that is suitable for you. I will ask you some questions and talk about your family with you. There will be time for you to say anything you think is important that you have not been asked. I would like to record the conversation using a voice recorder.

After we have spoken I will type up some parts of the conversation. I will use this information to write a report. I will not type up any details that may identify you, such as your name or the names of family members.

We might talk about:-

- What is important to you about your family?
- Who do you look after, and who looks after you?
- What has changed in your family life since someone became seriously ill?
- What is important for you in the future, and what might help you with this?

What might be bad about taking part?

There may be some things about your family life that might be difficult to talk about. It is fine if there are questions that you do not want to answer, and you can stop the conversation at any time.

What might be good about taking part?

Sometimes people find it helpful to talk to someone who does not know them or their family. Our conversation may help you to think about what you might need, and to talk to others who may be able to help.

We hope that this study may help people to understand more about what young people may need when a parent is seriously ill in the future.

Who will know what I have said?

Anything you say will be treated as private unless I am worried that someone is being hurt or is in danger. If I am worried, I will talk to you first about who else may need to know.

All the information collected about you and your family will be kept on a password protected database and will be strictly private.

What happens to the research report?

The report will be seen by senior members of staff at the university who are supervising this research. It may also be used to write journal articles or conference presentations. You and your family members will not be named in any reports or presentations. I will send you a summary of the report if you would like one.

What do I do now?

Please tell (your worker) if you think you might want to take part and I will arrange to meet you.

If you want to talk to me yourself, or if you want more information, you can contact me or you can contact my supervisor, Dr Kathryn Almack.

Our contact details are:

Nicola Turner	Dr Kathryn Almack
School of Health Sciences	School of Health Sciences
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APPENDIX 4: OUTLINE INTERVIEW SCHEDULE

Title of Study: Exploring the family lives of young people with a parent at the end of life

Name of Researcher: Nicola Turner

1. **Can you tell me a bit about your family?**
    a. Who is in your family?
    b. Age(s) of siblings?
    c. Who else is important to you/your family?

2. **What makes you a 'family'?**
    a. What kind of things do you do together?
    b. What is different about the relationships you have with your family members compared to other relationships?
    c. Who do you look after in your family, and how?
    d. Who looks after you, and how?

3. **Can you remember back to the time before your (parent) first became ill?**
    a. What was life like for you/your family at that time?
    b. How did you/your family respond when you first knew that your (parent) was ill?

4. **Did anything change for you / your family?**
    a. Did you/your family do anything differently when your (parent) became ill?
    b. How did these changes come about?
    c. How did you feel about the changes?

5. **What is life like for you now?**
    a. Do you discuss what is happening in your life with anyone?
    b. How is this helpful, or not helpful to you?

6. **In thinking about your future, how do you see your life?**
    a. What would you like to be doing?
    b. What might help you to achieve this?