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1 **Troubling meanings of family and competing moral imperatives in the** 2 **family lives of young people with a parent who is at the end of life**

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

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

17 **Introduction**

18 The anticipated death of a parent due to a life-limiting illness is generally perceived as
19 an extraordinary change in the life of a young person, and one that is understood as
20 profoundly troubling. However, little is known about young people’s everyday
21 experiences of living with dying. Research studies of young people with a parent who is
22 at the end of life have tended to focus on the negative outcomes of advanced parental
23 illness for young people (Huizinga et al. 2011; Rainville et al. 2012) and on strategies
24 for ‘coping’ (Maynard et al. 2013; Thastum et al. 2008). A limitation of this research is
25 that it considers the young person in isolation, often drawing on models of risk and
26 resilience to conceptualise young people’s experiences and responses to family
27 ‘troubles’ (Ribbens McCarthy, Hooper and Gillies 2013) as dependent on attributes

28 located within the individual. Less attention has been paid to relational aspects of young
29 people's everyday lives, or to the broader social and spatial context in which their
30 experiences of living with dying are situated.

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

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

52 practices that constitute everyday family life for young people when a parent is dying
53 and their experiences of both giving and receiving care in this context.

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

65 **Family, care and the 'good death'**

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

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

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

101 to offer their support are therefore raised by the importance of family presence to the
102 provision of ‘good’ end of life care.

103 The good death discourse that informs individual decisions about end of life care
104 may therefore privilege the option to remain at home, potentially transforming the
105 notion of choice with regard to place of death into a ‘de facto obligation’ (Pollock 2015,
106 3). Achieving a home death inevitably impacts on family members, especially those
107 who are co-resident with the person at the end of life. Research suggests that individuals
108 often take into account the presence of family members in making decisions about end
109 of life care (Gomes and Higginson 2006), although this process is far from
110 unambiguous or straightforward. For some, the reassurance that family members are
111 close at hand may support a decision to remain at home, whilst others may be more
112 influenced by concerns about being a burden on their family (Cox et al. 2013; Gott et al.
113 2004). These findings suggest that the conflation of spatial and psychosocial meanings
114 of home and family in the good death discourse may be a potential source of tension
115 between family members. Further research could help to explore how this tension is
116 manifested and resolved in and through everyday family life when someone is dying.

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

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

125 The importance of family care to end of life care provision has been reflected by a

126 growing body of research examining the roles, responsibilities and experiences of
127 family members in delivering care at home to people approaching the end of life.
128 Researchers have considered the process of becoming a carer (Smith 2009), the support
129 needs of carers (Morris 2015), and the efficacy of interventions to support carers
130 (Harding et al. 2011). However, a significant part of this research adopts an approach
131 that assumes a dyadic relationship between a ‘carer’ and a ‘cared for’ (Molyneaux et al.
132 2011). There has been less emphasis on the study of care at the level of ‘family’, and on
133 the everyday routines and practices that constitute family life in the context of providing
134 end of life care for a family member (Broom and Kirby 2013; Ellis 2013).

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

145 The *Caring to the End* study was based on individual, semi-structured interviews with
146 ten young people (age 13-21) and five significant others who were nominated by a
147 young person (four parents and one partner of a young person). Five of the young
148 people took part in the study along with a sibling, therefore the study participants were
149 drawn from six families in total. Not all of the young people nominated a significant
150 other; some reported that they were reluctant to approach their parent because the parent

151 was too ill to take part. Others struggled to identify anyone whom they felt comfortable
152 to approach. Characteristics of the study participants are outlined in Table 1. We have
153 chosen to present information about study participants in a way that does not explicitly
154 reveal the relationships between the young people and their significant others. This
155 decision has been taken to better protect the identities of participants. One issue with
156 studies involving multiple family members is that individuals and families may be
157 recognisable in research reports, even after any identifying characteristics have been
158 removed (Forbat and Henderson, 2003). By not providing more detailed information
159 about family composition, the aim is to reduce this risk.

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

161

162 [Table 1 near here]

163

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

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

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

185 The research interviews explored the everyday processes and practices that constitute
186 family life for young people, their experiences of caring and being cared for, and their
187 thoughts about their own lives both now and in the future. Young people’s accounts
188 were transcribed and analysed using the voice-centred relational method (Gilligan et al.
189 2003), a narrative approach involving multiple readings of a transcript to illuminate
190 different aspects of the young person’s account. The narratives of family members were
191 used to support a multiple perspectives analysis of how young people understood and
192 experienced the relational constructs of family and care (Ribbens McCarthy, Holland
193 and Gillies 2003). The multiple perspectives analysis involved reading the accounts of
194 young people alongside those of their significant others in order to identify similarities
195 and differences in how the concepts of family and care were manifested and described,
196 and how family life was constructed by young people *in relation* to those who are
197 important to them.

198 The presence or absence of significant others from the physical and psychosocial
199 space of home emerged as significant in young people’s accounts of living with a parent
200 who is at the end of life. This was most frequently expressed through references to

201 closeness and care. In the following discussion of the research findings, particular
202 attention is paid to how the presence/absence of others from the home space impacted
203 on the meaning and practice of family for young people, and how young people
204 responded to the moral imperative to ‘be there’ to accompany their parent as they
205 approached the end of life. All names attributed to young people are pseudonyms.

206 **Closeness, care and ‘being there’**

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

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

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

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

224 However, as Milligan and Wiles (2010) point out, proximity equates to more
225 than geographical closeness in that those who are physically distant can be socially and

226 emotionally proximate. The young people in our study also applied the notion of
227 closeness to describe the emotional bonds between family members; in particular, bonds
228 that had been tested but proved resilient in the face of parental illness. For example,
229 Luke described his family as ‘pretty strong’, but went on to explain how relationships
230 between family members had been strained:

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

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

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

276 that the notion of being there may be imbued with particular significance by young
277 people during troubling times.

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

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

287 *(Dan, 16)*

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

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

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

301 *(Lauren, 21)*

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

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

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

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

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

321 Whilst it is likely that the absence of extended family would not have been as
322 keenly felt by young people in less difficult circumstances, the physical and emotional
323 absence of family members in this study was something young people struggled to
324 reconcile with the meaning of family. The heightened awareness of what family
325 members *should* be doing in terms of *being there* is augmented by a social narrative of
326 accompanied dying at home as essential to the fulfilment of a good death. Home is

327 therefore reimagined as a moral space in which the significance of home and family as
328 interconnected sites for the formation and enactment of moral identities is reinforced
329 (Hall 2016). In their accounts of everyday family life, young people were often engaged
330 in the telling of a moral tale, in which they explored the legitimacy of their family's
331 claim on being a proper family by assessing the extent to which family members
332 (including themselves) met the responsibility to be there.

333 **Moral tales of being there**

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

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

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

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

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

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

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

376 In a study of families facing change, Ribbens McCarthy, Edwards and Gillies
377 (2000) suggest that in responding to family troubles there is a discursively apparent

378 moral imperative to put the needs of children first. They report that this ‘unquestioned
379 and unquestionable imperative’ (2000, 789) was subscribed to by all of the parents
380 interviewed for their study, at least to some degree. However, when a parent is at the
381 end of life, the actions of young people and family members appear to be shaped by a
382 competing moral imperative to attend to the needs of the dying person. This shift away
383 from family as a site for nurturing children towards family as a space to care for the
384 dying may begin many years before the point of death; for example, when a life-limiting
385 illness is first diagnosed.

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

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

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

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

404 her Mum:

405 *When we were growing up, there was always a safety net. Mum was always*
406 *the safety net, you know. Whenever I had a problem or I didn't know what to*
407 *do or how to do it, she always did, or if she didn't she soon would. Whereas*
408 *now I feel like - up until she was really ill, I still felt, not like a child, but like I*
409 *could be a child. But now it feels like a change. It feels like I'm not a child any*
410 *more. Not that I've got to fend for myself, but like I don't have that safety net*
411 *any more. (Lauren, 21)*

412 Lauren's account illustrates how she had responded to the growing awareness that her
413 Mum was no longer able to meet her needs by 'turning the tables' and being there for
414 her Mum:

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

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

424 Wilson's (2013) account of the absence of expected family practices for some young
425 people affected by parental substance misuse illustrates how a young person's
426 experience of loss may be compounded by a sense of having breached their own moral
427 obligation to family by not being there for their parent. This suggests that a young
428 person's moral self may be at stake if they are unable to sustain a moral tale of
429 closeness and care between family members. Stepping in to provide care for a parent

430 whose ability to care for them had become compromised by their illness therefore
431 served the dual purpose of maintaining the family's moral reputation and preserving the
432 young person's own moral identity.

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

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

450 **Conclusion**

451 In this paper, we have drawn on an empirical study of young people's accounts of living
452 with a parent who is at the end of life to describe how the construction of 'family' is
453 characterised by notions of presence, closeness and care; meanings that were informed
454 by everyday experiences of absence, change and loss. For young people in our study,

455 home represented a physical and a psychosocial space where they were doubly troubled
456 by, on the one hand living with dying, and on the other by belonging to a family that
457 had fallen short of expectations of family members being there. We have described how
458 home as a place of care *by* and *for* family members is underpinned by the social
459 narrative of a good death, and we have explored how the good death discourse interprets
460 and promotes home as a moral space through the construction of a proper way for
461 family members to respond to the presence of dying.

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

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

480 themselves. The changing moral imperative for family when a parent is dying is
481 therefore understood, experienced and negotiated by young people through relational
482 practices of care.

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

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

505 the home space, and on enhancing the everyday experiences of all family members over
506 the trajectory of a life-limiting illness.

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