

Title: Moral ambivalence and informal care for the dying

Abstract:

Caring for the dying presents perhaps the most challenging site of informal care. Participation in informal caring roles in such contexts has been prone to reification as a virtuous social practice, often without critical reflection as to the implications for caregivers. Here, drawing on interviews with carers who were providing care in the last few weeks or days of life, we develop an understanding of informal care in this setting as a morally ambiguous social practice, framed by social relations of duty, gift and virtue, but in turn encapsulating experiences of failure, shame, and suffering. Such a contradictory understanding of caregiving is critical for understanding the tensions within end-of-life settings and also for countering the concealments produced by the valorisation of informal care more broadly in modern societies. We present a critical analysis of informal care's contested character at the end of life, challenging normative understandings that are complicit in producing moral ambivalence, shame and suffering for individual carers.

Introduction:

Most of us receive some form of care when we are dying. Informal care – i.e. care provided by family or close friends – is often central to the dying process (Thomas et al., 2002). Captured by the oft-cited phrase ‘they passed away peacefully surrounded by family and friends’, informal care is central to the cultural imaginary of a good death, denoting such things as closeness, reciprocity, intimacy and closure (Broom et al., 2013; Broom 2015; Kirby et al., 2014; McNamara, 2004). Such portrayals, which situate the ‘good death’ as indicative of social successes, i.e. as the completion of a *good* life surrounded by *close* family and friends, often do not hold up in practice as evident in broader scholarly work on the cultural reification of ‘dying well’ (e.g. Chattoo and Ahmad, 2008; Lawton, 2000; McNamara, 2004). The disjunction between the normative and the lived experience, we argue here, can have important and often problematic effects. Specifically, such cultural scripts offer informal carers the opportunity to illustrate a range of culturally-valued characteristics (Broom et al., 2010; Chattoo and Ahmad, 2008), producing positive experiences as well as considerable moral ambivalence as carers variably accept, resist or reject these normative facets of caring well (cf. Sayer, 2005). While the moralities underpinning informal care – particularly gendered, familial dynamics – have been explored previously (e.g. Bracke et al., 2008; Finch and Groves, 1983; Gorden 1996; Held, 1995, 2005; Kittay, 1999; Larrabee, 1993; Tarlow, 1996; Tronto, 1993; Ungerson, 1987; 2005), there has been relatively little sociological work completed on the moralities of informal care for the dying and their affective dimensions. This is a gap in our understanding of informal caring relations we engage with here.

Retaining a focus on informal care is particularly important given the current sociocultural context within which opportunities for participation in informal care are shifting (Bailey and Robertson, 2015). Informal care is an increasingly precarious ‘commodity’ (cf. Benería, 2008). Traditional and often gendered models of informal caregiving continue to be challenged (often productively) by a wide range of social forces including: shifting family structures and gender roles; dual income families; global mobility and familial distance; processes of detraditionalisation and a broader weakening of kinship ties (Broom, 2015, Broom et al., 2013; Benería, 2008). In turn, the practice of informal care at the end of life in OECD contexts takes place amidst

steadily retracting welfare states, economic tightening, and other challenges to family and community life (Bailey and Robertson, 2015; Benería, 2008; Beck and Beck-Gernsheim, 1996). Following Sayer (2005), we posit that these intermingling social forces raise important questions including: what care should and can be provided for the dying, who will provide it, and how will new relations of care be experienced? Further, what (if any) is the enduring cultural value of informal care and what level of commitment can thus be shown to it?

We emphasise that our aim is not to adjudicate the ethics or value of informal care for the dying, but rather take morality (and forms of moral ambivalence) as related to attempts to answer the often implicit question ‘how should one live’, or in this case, die. Further, we highlight the problematic effects of overly idealised representations of end-of-life informal care for the very people who provide that care, namely the moral ambivalence, shame and suffering experienced by informal carers. This is revealed in the experiences of our participants who invest considerable energy into the moral calculus of assessing the goodness (or otherwise) of their actions. We posit that revealing the shifting pressures involved in participation in informal care and challenging the normative constructs surrounding end-of-life care that are complicit in producing the sense of failure experienced by informal carers is an important task for sociologists.

Background:

Informal caregiving in scholarly context

Much of the considerable scholarship on informal care shares the premise that the practices and experiences of informal caring are “valued privately, romanticised publically and largely invisible to society” (Gorden et al, 1996: p. viii). Similarly, within feminist scholarship, care and caregiving have been characterised as part of the (often hidden) burden of women’s social position and identity (Bubeck, 1995; Mol, 2008). Finch and Groves (1983) and Larrabee (1993), for example, explored key dilemmas around agency and choice versus gendered obligation in participation in care. Much of this work centred on the exploitation of women in caregiving, and the complicity of informal caring relations in the perpetuation of gender inequality and barriers to social justice (e.g. Baker Miller, 1976; Clement, 1996; Gilligan, 1982; Graham, 1991; Poole and Isaacs, 1997; Ungerson, 1983). Several scholars have sought to unsettle notions of care as imposed (i.e. obligation, structure) or desired/expressed (i.e. gift, reciprocity, fulfillment); rather positioning caregiving as an assemblage of the relational, normative, discursive and affective relations (e.g. Held, 2005). Such work has included analysis of an ethic of care, situating caring as a morally correct disposition towards others and as central to human life (Held, 1995, 2005; Goodin, 1985, Tronto, 1998).

There has also been a focus on disentangling the dimensions of care, including its affective (i.e. loving aspects of caring) and practical/physical dimensions (Ungersson, 1987; Kittay, 1999; Parker, 1993). Such analysis has inserted complexity into understandings of different sites and spheres of informal care, illustrating that providing and receiving care is mediated by identity, roles and institutional setting and is imbued by power, authority and dependency (Graham, 1991; Kittay, 1999; Tarlow, 1996). This point is vital to the current study where we focus on care within an in-patient setting. In this paper, we reveal the affective elements of care that are often concealed by frameworks of moral obligation (Parker, 1993, Twigg and Atkin,

1994; Bracke et al. 2008; Berecki-Gisolf et al. 2008), to highlight the potential moral bind of care at the end of life. Of particular importance here are relations and experiences of 'choice and virtue' and 'failure and shame'.

Choice and virtue

Despite the considerable aforementioned work on informal care over the past few decades - including the moralities therein - the moral dimensions of informal care at the end of life have received little attention; when considered in its normative framing (Sayer, 2005), this form of care *should*, simply, be done. In dying one's significant others should be present, be involved and care. Such logics entail limited rationales for refusing to participate in informal care for the dying and importantly, few means for withdrawing it based on cost-benefit assessments (see Ginn, 2013; Sayer, 2005). Care for the dying's seemingly choice-less character is intertwined with its potential for the articulation of virtue, or as it may be for some carers, the experience of failure and shame (cf. Arksey and Glendinning, 2007). Informal care often involves ongoing self-assessments of moral virtue (Sayer, 2005). This in turn means social pressures on carers to undertake particular activities and roles in order to feel like they are moral beings. There is, of course, nothing wrong with informal care being ascribed, or informal carers experiencing, virtue; nor is the broader pursuit of virtuosity in social life *a priori* problematic (cf. Flanagan and Jupp, 2001). However, such normative social scripts can become extraordinarily complex when we consider why certain acts are deemed virtuous and who has the opportunity to enact them.

Problems may emerge, for example, when the virtue ascribed to the informal caring role becomes untenable in the social circumstances within which one lives (Ginn, 2013), including the presence of structural conditions that allow only certain people to flourish within such relations (cf. Benería, 2008; Held, 1995). Changing socioeconomic conditions may also mean that for some people, the rewards emerging from an activity like informal care for the dying may simply not be enough to warrant the costs; and even more problematically, that more privileged members of societies are able to experience virtue due to their enhanced capacity for participation, while others may experience only failure and shame (Held, 1995).

We can add to this aforementioned problematic of virtue that understandings of informal care can become self-disciplining and are deeply embedded in structures of authority and expertise (cf. Ungerson, 1987). For example, the idea that carers should accept death when and as it comes (*vis-à-vis*, for example, assisting dying) is one assumption that can sit in distinct contrast to individual and collective desire (cf. De Jong Gierveld and Dykstra, 2008). Thus, social mores - such as the value of waiting, or the virtue of stoicism at the end of life - are inseparable from structures of power and authority (Held, 2005). Given this, there is an urgent need to account for the hugely diverse and even disruptive experiences of informal care for the dying. Further, there is a need to understand how failing to account for these disruptive experiences reinforces the valorisation of informal care in modern society. Two vital disruptive experiences are those of shame and guilt

Failure and shame

Feelings of shame and guilt can emerge from people's evaluative judgments of their lives, reflecting individual's moral assessments of how they are faring amidst a wide range of social expectations including those related to informal care and beyond (e.g.

balancing roles in the family, workplace, friendships) (Ginn, 2013; Sayer, 2005). In other words, shame and guilt derive from a negative assessment of how one is *actually* living against the normatively prescribed answer to the question, ‘how should one live’. As Sayer (2005) argues, sentiments such as shame, envy, resentment and contempt are not just forms of affect, but can represent a sense of success or failure of an individual or group to live according to dominant values. They can thus be viewed as the affective outcomes of lay normativity surrounding various social roles and illustrate the deep intermingling of the emotional and moral dimensions of caring relations. As we explore in the results below, negative moral self-assessments occur regularly in the context of caring for the dying and contribute to carers’ moral ambivalence, sense of failure and shame. We reveal a persistent questioning amongst informal carers around their capacity to *achieve* care at the end of life, and most importantly, to have positive self-evaluations *in relation* to it. We argue that a key task for sociologists is to capture conflicted experiences of informal care at the end of life – and the moral ambivalences they can produce – and in turn, examine how these may articulate broader contemporary social relations.

Methods:

We employed a qualitative inductive approach, using semi-structured interviews to investigate the experiences of informal carers in a specialist in-patient palliative care unit in a major metropolitan area of Australia. After receiving ethics approval, we recruited informal carers who were caring for patients in the last few weeks or days of life. The ‘treating’ clinician would make the initial approach by explaining the study and asking if the carer might be interested in taking part. The researcher was then provided with the details of informal carers who had agreed to have their details passed on, so that an interview could be arranged.

A total of 37 interviews were completed (23 female, 14 male and aged between 30 and 89) with carers of patients with advanced cancer. Interviews lasted between 15 minutes and 1.5 half hours, were semi-structured and sought, where appropriate, to cover: the meaning and everyday practices of caring for someone who is dying; experiences of caring before, during and post transition to in-patient care; the possibilities and limitations offered by the caring role; and broader personal and existential reflections on the dynamic of caring for someone at the end of life.

Organisational and Caregiving context

Referrals to the in-patient unit came from the community palliative care service (about two-thirds) and other tertiary referral hospitals (one-third) in the area. Most of the participants had recently transitioned from involvement in wide-ranging caring roles in the home. Often this transition was due to complex symptomatology, which could not be controlled at home, leaving carers almost exclusively focused on emotional care given the institutional environment. This provides an important context to a potential sense of failure or shame in not being able to offer different forms of care. Most participants were kin caregivers including 7 husbands, 7 wives, 2 long-term partners, 1 brother, 2 sisters, 4 sons, 11 daughters, 1 mother, 1 granddaughter, and 1 grandson). Most patients had a range of complex cancer-based symptoms and the results thus illustrate both broader dynamics of care and the difficulties faced by lay caregivers in managing cancer-related symptoms.

Analysis

The methodology for this project draws on the interpretive traditions within qualitative research, specifically on Charmaz's approach to social analysis (1990). The approach to data collection was developmental; knowledge generated in early interviews was challenged, compared with, and built upon by later insights and experiences. We approached the analysis of the interviews thematically, seeking to retain the richness of the respondents' experiences, documenting atypical cases, conflicts, and contradictions within the data. Finally, we revisited the literature and sought out conceptual tools that could be employed to make sense of the patterns that had emerged from the data.

Results:

Waiting and Knowing

While the participants were all acutely aware that death was coming, a key theme within the interviews was the precariousness and uncertainty about when *exactly* this would occur and the implications for carers' capacity for care. This experience relates to the broader dynamic within informal care at the end of life, and how uncertainty around timing of death, the course of illness, and the trajectory toward dying, is experienced (Honkasalo, 2006). Such uncertainties create ambivalence around how much resilience is needed, the degree of commitment required and practical considerations about managing participation in one's normal life (pre, peri and post the dying process). While caring for dying in-patients may seem like a fairly predictable site of informal care (i.e. most of those being cared for in an inpatient unit would be expected to die within days or weeks), the acute challenge of uncertainty was palpable in the interviews. These accounts reflected a tension between needing to know - to identify an end point to carer and patient suffering - and wanting the person to live. The act of asking clinical staff "how long" was often described as taboo in the context of offering of loving, unconditional care - a dynamic talked about as produced concurrently by the perceived expectations of clinicians and carers' own desires to balance knowing versus unconditional care:

... [death] it's been hanging over our heads sort of for two and a half years ... the last six months have been the hardest I think because it's coming, it's coming ... So it's just there waiting, you're just waiting, waiting, waiting. Your expecting that it's going to be here soon, anytime you think. You just don't know. [Relationship: Wife. Patient details: Colorectal Cancer, Male, 60-69]

Such uncertainties around time and time left were compounded by a general reluctance on the part of clinicians to specify estimates around the dying process:

Most people [health professionals] don't want to tell you too much...I'd ask things like "what's an average timeframe for this to keep going?" And no-one really wanted to give me an answer. And I kept saying to them "I know everyone's different, I won't hold you to it, I just want to know the average. Is it five years? Is it one month?" [Relationship: Daughter. Patient details: Bladder Cancer, Male, 80-89]

The uncertainty around whether death was close, and subsequent feelings of moral ambivalence around what was reasonable to *ask* of carers (e.g. "how long can I do this") or *feel* (e.g. "I can't do this"), was critical to experiences of informal care in the context of dying. There were a range of responses to the problem of uncertainty, with some taking the approach of "we need to know", while others would "roll with the punches", as one participant stated. This latter approach was talked about as involving

dyads of stoicism, evidenced in numerous accounts of pretending to “handle it” or “be strong”:

How do I do it? ... my dad said “how come you’re handling it so well?” And I said “well, actually I’m not, I’m just trying to be strong for both of you”... I said “I had to because what choice did I have? I can’t fall down in a heap because it’s [death] still going to be there.” So you get yourself through it and then you fall in a heap afterwards. [Relationship: Daughter. Patient details: Breast Cancer, Female, 80-89]

Underlying the above-mentioned accounts was a dynamic of informal care for the dying as unconditional and non-contingent - never ending and in ample supply. The normative logic, acutely felt by the participants, was that a proper caring relationship would be authentic to the natural order of dying, rather than *making demands* of it. Their experience of care, however, was far more complex, with their offerings implicitly contingent on balancing the capacity to emotionally invest over the course of the dying process. Whilst dying was “handled well”, often underneath the surface, they were desperate to know when death would occur despite their external performances of strength and stoicism. Grounded in the dynamic of waiting versus knowing, stoicism and strength were viewed by participants as finite resources, and only to be performed until the patient’s death (and often funeral). For the majority of participants, there was an expectation that they would “fall in a heap” once death had occurred, and that such stoic behaviours represented a *temporary* enactment of duty. Stoicism, then, is enacted at least in part to avoid the shame of not caring enough (e.g. admitting to thoughts of being “fed up” with caring). Put differently, the moral ambivalence experienced around waiting versus knowing results from a discordance between the diverse experiences of caring for the dying and dominant cultural scripts around duty and dying well.

Duty and Regret

The importance of performing one’s duty was a dominant narrative throughout the participants’ accounts, with a distinctly moral rationale for participating in informal care despite the burden or grief involved. Several participants explicitly stated that they came each day “out of duty” whereas others talked about their responsibility to “pay back” the person being cared for (i.e. for what they had done for them across the life course). This was both temporally located - a form of exchange based on what was considered right and good - and a moral position for the carer, with explicit and implicit acknowledgement that this would likely be reciprocated by others in the future. Duty was especially prominent intergenerationally, with children or grandchildren emphasising the role of duty much more so than partners.

Carers drew on various logics surrounding duty including ascribing forms of virtue and moral goodness but also situating these relations within specific cultural values. For example, commitment to informal care was positioned by some as “an Australian thing”, by others as an “act of giving back”, and by still others as something that “good people do”, indicating a subtle interplay of aspects of cultural identity, social mores, moral practices and local caring practices:

...it’s a basic Australian thing isn’t it? Comradeship, your parents bring you up, they look after you, you’ve got to give something back in return. And that’s not a cliché mate, that’s just exactly the way it should be. [Relationship: Son. Patient Details: Breast Cancer, Female, 70-79]

Another respondent:

Yeah. She's been good to us over the years, so you know, you don't want to think of her just sitting here by herself. [Relationship: Grandson. Patient details: Leukaemia, Female, 90-99]

Much of the drive to fulfil one's duty was situated as avoiding anticipated posthumous regret of not spending enough time with the dying person and not caring sufficiently. This was often articulated as not wanting "to have regrets" and wanting to "live with myself afterwards":

[B]ecause I'm away down in [respondent's home suburb], I figure "while I'm here I should spend as much time as I can with them". Because I know I'm going back and I don't want to have regrets of "you went back and you shouldn't have gone back, you should've stayed." And that's my concern...I don't want to have regrets. [Relationship: Daughter. Patient details: Breast Cancer, Female, 80-89]

These various tensions were succinctly captured by one participant who commented that, as a carer, you're "damned if you do and damned if you don't".

Although not the focus of this paper, it is important to note the gendered tendencies of such moral accounting. In line with broader gendered experiences of informal care, the men interviewed tended to situate their duty within cultural norms or as "doing the right thing", whereas the female participants tended to articulate this as "not letting them down" or "not having regrets" (Broom et al., 2010a; Chattoo and Ahmad, 2008; Held, 2005). These and other articulations of duty and avoiding regret were enmeshed with a broader notion of *giving* across the life course based on the underpinning assumption that we will all require care at some point. What we can see here are the (often gendered) rationales for care and how people make sense of the inherent difficulties of investing time and energy into such a precarious and overwhelming moment.

Place of Care, Transitions, and the Permissive Moral Boundary

While the interviews were completed with informal carers in the inpatient context, the transition from home to institution was often a central point of discussion. There are important reasons for this, including how locale - and subsequent relations of authority, reliance and release - mediate informal care. Importantly, a sense of moral failure as a result of the transition to inpatient care was evident across the interviews with carers. These transitional experiences provide insight into the normativity of informal care and carers' experiences of shame. The transition to formal inpatient care was often articulated as the product of a lack of coping at home and in terms of abandonment or failure:

The first week [here] was really hard because, well first of all just the dealing with leaving her here which I found a bit difficult. Not because I wasn't happy with the care... I think it's just an emotional stumbling block, you feel as though you're abandoning them. [Relationship: Daughter. Patient Details: Bowel Cancer, Female, 80-89]

The interviews also revealed how normative ideas about sacrifice, duty and gift (or lack thereof) may interplay with capacity and willingness to transfer to and/or die in an institutional setting:

I remember saying, “I have looked after Pop for all these years. I’m going to make him go somewhere like this?” And I actually felt that I had totally failed him...Last Thursday night... he wanted to come home with me. I said “Pop, I can’t take you home, you’re too sick.” ... And he said to me “do you want me to die in here?” And I said “Pop, this one time I just can’t do what you ask of me...” And after that he really didn’t eat that much anymore... [that was it] [Relationship: Granddaughter. Patient details: Bladder Cancer, Male, 90-99]

Another respondent:

I: How do you feel about him being here then?
Has to be, doesn’t it...? Well I can’t do it...it’s just that I feel a bit of a rat, putting him in. But I just can’t handle him at home anymore...It’s just that deep down I feel as though I’ve done the wrong thing. [Relationship: Wife. Patient details: Colorectal Cancer, Male, 80-89]

Participants described how clinicians often (unwittingly) reinforced normative ideas about selflessness in their attempts to rationalise the transition to formalised care. While interviewees reported that clinicians emphasised the need to “be selfish”, mobilising the notion of ‘being selfish’ risks reinforcing the transition from informal to formalised care as a form of personal failure on the part of the carer:

And the doctor said to him [patient] the other day “she [wife] is too tired to look after you now, you know you have to wait, she can’t look after you if she’s too tired, you keep waking her up all the time”. And [doctor was] trying to get through to him. She said [to me], “you have to be selfish.” [Relationship: Wife. Patient Details: Colorectal Cancer, Male, 60-69]

This rhetorical turn can be read in a number of ways. On the one hand it gives tacit permission to these carers to stop (unconditionally) giving and caring, in order to prevent burnout and allow a transition to formalised care. In this, it can be read as contravening dominant cultural scripts of selfless duty at the end of life and as illustrating to the carer the reasonable limits of their efforts. Yet, it also draws on a binary notion of informal care as embedded in gift/sacrifice versus withdrawal/selfishness and positions withdrawal of care as *inevitably* selfish. In this, it can be read as reinforcing dominant cultural scripts around selfless duty.

Other participants had quite different experiences of the transition to formal care, seeing the decision to move from home-based (informal) to inpatient care as a medical moment beyond the remit of the informal carer:

Well we just sort of went with what the doctors said. I mean I don’t really know that you could opt not to engage in palliative care, you know? So it’s just automatic, it’s just part of the journey...a while ago she felt that she wanted to die at home but has since changed her mind. Mainly I think she feels it would be too much for me. I mean I’m not sure if it would or it wouldn’t, I’d meet the challenge...[Relationship: Partner (female). Patient Details: Ovarian Cancer, Female, 30-34]

Indeed, several participants' accounts included circumstances where they felt it was not reasonable to expect home-based, exclusive informal care:

She wants to die at home and as much as I'd like to give her that wish, I'm not sure that I can carry that burden because she needs too much help. [Relationship: Husband. Patient Details: Lung Cancer, Female, 70-79]

Here the moral ambivalence surrounding the transition to palliative care is complicated by the necessity of high-level specialist care. But for other carers, inpatient care was articulated as positively transforming and as improving their capacity to provide care, offering considerable relief for both them and the person being cared for:

[The inpatient unit] it's a godsend really [interviewer's name] it's a godsend. Because at home if she has a pain, you can't do anything. [Relationship: Partner (male). Patient Details: Cervical Cancer, Female, 80-89]

Within these excerpts a range of important dynamics are apparent. On a practical level, these accounts may subtly reflect (for some participants) the delicate interplay of resources, professional and social support, the provision of informal care in the home, and individuals' senses of moral success or failure. We can also see how gender affects how participants rationalise their role in the transition to formalised care, with the female carers often expressing a greater sense of moral failure as a result (Berecki-Gisolf et al., 2008; Harding and Higginson, 2001). What was clear across the interviews was that the transition from informal to in-patient care represented a permissive moral boundary that, once traversed, variously enabled informal carers to be something previously considered immoral – i.e. 'selfish'. In sum, location of care clearly inflects the moral negotiation and affective dimensions of informal caring relations. Those in positions of authority (doctors/nurses) may play a key role in both facilitating transitions and the dynamics of permissiveness for balancing the burden of care. It is likely, we posit below, that when such boundaries are blurred and/or unarticulated, or caring responsibilities become too burdensome, problematic relations emerge that further challenge carers' subjectivities as moral and ethical beings.

Taboo Feelings, Hoping for Death

What occurs when we feel what we should not in end-of-life contexts? When that which is taboo becomes the dominant feeling or experience for an individual or family? We argue that being or feeling uncaring has been relatively neglected (vis-à-vis the value of participation in caring relations) in the literature on end of life care (though see Broom et al., 2011; 2012). Such problematic experiences were on a spectrum for these participants, and often were reported to change throughout the dying process. Their self-defined immoral feelings (i.e. those they defined as "not right") were often about such things as wishing the person would not wake up or feeling resentful. Whilst not universal, many carers experienced tensions around whether these experiences were allowable and thus able to be articulated. Most described these feelings and experiences as forms of personal moral failure, sometimes reflecting on the process of care as a form of "turmoil" and "torture" for the carer. Hoping for death was a "dark secret" often reluctantly admitted:

So this [caring] is a very, this is really quite hard. There's a lot of uncertainty, I guess there's a certain amount of loathing and blackness.... [caring] it's like a form of pain or torture for every individual I think. [Relationship: Son. Patient Details: Liver Cancer, Female, 90-99]

For some participants, ambivalence around the death of their relative was a product of familial discord, or the acknowledgement of family personalities or dynamics that fell outside normative constructions of the good death (McNamara, 2004):

Another thing I've found, this is dealing with mum, she was a cunning old bugger! And she was mean too. People don't change when they get old, they don't turn into sweethearts. If you were a nasty bugger all through your life, you are when you're old...everyone takes the [side] of the elderly, as if they're all lovely old grannies and grandpas... there's always this assumption [of us]. When mum died, I just felt nothing... I don't know how I'll feel when he [father] goes. I think it will be like a huge burden [is gone]. [Relationship: Daughter. Patient Details: Colorectal Cancer, Male, 90-99]

Such moral ambivalence around death was not isolated to familial discord or dysfunction. Indeed, many of the participants who described their relationships as close and loving also experienced contradictory feelings including the hopeful anticipation of death:

...mine are funny tears. Mine are tears that I'm losing someone but behind it is the sooner [he dies] the better...I've come to terms with my grandfather because it's the best for him and [living] it's not what he wants. [Relationship: Granddaughter. Bladder Cancer, Male, 90-99.]

Another respondent:

... you've built up to him going and then...it's a letdown, it's awful, but a letdown when he doesn't [die]. Because I mean you've built yourself up thinking "this is it, this is going to be the end, it's going to happen" and then when it doesn't you think "oh, ok, here we go again," and you're sort of up and down up and down, it's stressful. You're sort of preparing yourself and building yourself up for this "god he's gonna die," and he doesn't. (laughs) Does that sound [awful], do other people say this sort of thing?... Because I wonder sometimes if it's just me, am I the only person that thinks like this? [Relationship: Wife. Patient details: Colorectal Cancer, Male, 60-69]

One of the dilemmas faced by these carers was that the relationships they had with the person who was dying had often changed fundamentally over the course of illness and the dying process. The idea that people "turn into sweethearts" when they age was challenged by numerous participants who questioned the character and quality of their relationships and the impact of investment in informal care therein.

A particularly common, but taboo, thought was the problem of patients living too long and the limits to duty, stoicism and ultimately carer's offerings of care:

He was pretty sick when he got here. And I think we all thought that he wouldn't make it through the next week. But they stabilised him so well that he picked up...it was sort of like "well, does he have to come back home? How am I going to look after him?" That was a really anxious time... [Relationship: Daughter. Bladder Cancer, Male, 80-89]

Another respondent:

I have to go home sooner or later. I mean I have an 85-year-old husband. How do you balance it...? I said to my husband, I said "if [name of patient] is deteriorating fast, I will stay as long as is needed." But at the moment...I mean she's sick I know, but she's not deteriorating really fast... I just think "well, she could go on like this for a couple of months"...let's say that we're very, very happy that [patient's name] is [here]. We hope that she can stay here until the Lord decides that it's time for her to go home to heaven. I couldn't think of a better place for her to be in. [Relationship: Sister. Patient Details: Lung Cancer, Female, 60-69]

It is worth considering these feelings and experiences in relation to the complex interplay of formal and informal care. Here many of the carers interviewed have traversed the permissive moral boundary accompanying the transition to formalised care and have thus been permitted to express (immoral) relief. Having accepted the burden of care is now too much for them to provide at home, they are then reluctant to return to previous arrangements. They thus find themselves hoping/wishing for the person to die – for a good death within the palliative care unit - or at the very least, wrestling with mixed and competing feelings, often diverging significantly from normative moralities of grieving family members. Put differently, they experience acutely the moral ambivalence described by many informal carers at the end of life.

Discussion:

What emerged in this study of carers' diverse accounts of the dying process was a series of tensions between dominant cultural scripts and individual experiences of informal care at the end of life. Tensions around waiting and knowing, loathing and caring, duty and regret, stoicism and release, gift and withdrawal etc., reflected a series of moral and normative struggles for informal carers. Some may argue that such struggles are normal aspects of the relational character of dying - that dying-caring dyads are often conflicted, tense and contradictory in character and perhaps 'naturally' morally fraught. Yet, we posit that these participants' stories illustrate more than just normal interpersonal relations at the end of life. Rather, they point to sites of suffering that can ensue from disjunctions between normative cultural idealisations of caring/dying and the moral ambivalence experienced by informal carers at the end of life.

Although commonly used to connote an affective position of uncertainty or indecision amidst contrasting options, as a psychosocial concept and in our use of the term, ambivalence describes the experience, simultaneously of contradictory views or feelings. Smelser defines the term as "the simultaneous existence of attraction and repulsion, of love and hate" (1998: 5). We note that scholarly investigations of ambivalence have tended to focus at the level of individual psychology and have often failed to account for socio-structural dimensions, i.e. the networks of interpersonal and broader social relations that shape individual and collective affective states (though see Hillcoat-Nallétamby and Phillips, 2011). Sociological investigations of ambivalence, however, situate the contradictory affective experience within broader social relations (Merton, 1976), group and institutional behavior (Smelser, 1998), conditions of modernity (Bauman, 1991; Beck 1992), and/or ontological in/security (Giddens, 1990). Anthropologist Arthur Kleinman has described the social shaping of individual subjective states using the idea of social suffering. Suffering, he argues,

and responses to it, result from the “reciprocal influence of shifts in cultural representation, social experience and subjectivity which are shaped and reshaped by epochal political, economic and social structural transformations” (1997: 322). As a result, moral ambivalence and the suffering that can ensue, can be seen as a result of the disjuncture between cultural idealisations of informal care at the end of life and the social experience of providing that care.

A key element of this suffering was the experience of feelings of shame or guilt. We note that to be ashamed requires a notional audience - an imagined community of upholders of cultural representations and social expectations. In contrast to guilt, which is a personal/private negative assessment of particular actions against one's own standards of behavior, shame tends to be a more generalised experience of suspected moral failure – i.e. a threat to one's worth as a moral being. Because shame often has its locus of control outside of the individual subjected to it, unlike guilt, which can motivate future behavior change, shame often entails feelings of powerlessness. The majority of the carers we interviewed felt significant shame related to their ambivalence around providing care. What is interesting is that unlike some other prominent acts of shaming (cf. Jacklet, 2015), the shame expressed by some of these participants has no easily identifiable source or perpetrator. Rather, we suggest it belongs to part of the cultural imaginary of caring for the dying. Put differently, it is the dominant normative cultural scripts around informal care and dying that contribute to the moral ambivalence and social suffering experienced by carers. Culturally we tend to privilege the former in a series of problematic binaries: home/institution, personal/impersonal, gift/commodity. However, the ‘realities’ of care for the dying may compel us to engage with the latter. Failing to engage with the lived experience of informal care at the end of life cannot help but perpetuate the sense of moral failure and shame that some carers currently experience.

It is worth reiterating the context of this study; these accounts were situated in the particular institutional space of an in-patient unit and thus many of the participants' moral tensions revolved around the home-institution ‘transition’. As Gordon et al. (1996 p.viii) point out, locale is a critical component in understanding the dynamics of care given that contemporary societies have added complexity to caregiving needs through the very ‘accomplishments’ that were supposed to address such needs (i.e. hospice or specialist in-patient palliative care). Indeed, the transition to in-patient care forms a destabilising moment that gives analytic purchase on questions of what should be done – i.e. questions that invite moral reflection. The moment of transition from home-based to institutional care thus provides a critical lens into specific forms and moments of moral ambivalence as experienced by carers. In contrast to the home environment, where the logistics of care demand considerable attention, in-patient care provides for patient's physical needs, leaving carers largely to provide emotional care. Carers who are negotiating the transition to in-patient care are particularly well poised to reflect on the emotional dimensions of care. Furthermore, because moments of transition disrupt the status quo, they unavoidably invoke questions of what *should* be done, i.e. they invite moral reflection on different courses of action and their attendant emotional rationales and results.

Moreover, dying is a moment in the life course particularly prone to moral dilemmas, where traditional dynamics around duty, absolution and regret may be more acute than in other informal caring relations. While we have not focused in here on the

specificities of different relationships (whether partner, child, parent, friend) it is certainly clear that dilemmas will be situated within cultural ideas about 'blood', 'marriage', 'kinship' and so forth – and that normative social scripts will be experienced differently according to the dynamics of role expectations. In addition, it is worth making explicit the socioeconomic location of the majority of our interviewees, who were largely well educated and economically secure. That is not to suggest that normative social scripts are *necessarily* experienced differently by inhabitants of different socioeconomic positions, but rather, to suggest that moral ambivalence around end of life informal care may be amplified by the (relative) luxury of choice and reflection. For caring units that experience greater constraints - inflexible work arrangements, an absence of carers' leave, necessity and urgency of workforce participation etc. - *necessity* may prevail with differing consequences for moral questioning. However, this highlights the changing character of 'home' in capitalist economies and how the home is increasingly structured as an economic unit, with implications for relations of care. If providing informal care presents an opportunity for carers to exhibit moral virtue, the precariousness of informal care means that many are limited in their opportunities to enact virtue and follow the normative cultural scripts surrounding familial closeness at the end of life.

Like other informal relationships, informal care at the end of life is situated within interplaying cultural and economic influences (De Jong Gierveld and Dykstra, 2008). The changing nature of family structures and gender roles, general weakening of kinship ties, changing workforce participation rates, global mobility, steady retraction of the welfare state and global rise of neoliberalism all challenge (often productively) the 'traditional' family and its associated divisions of labor. Participants' problematisation of, and even resistance to, the idealisation of loving and caring familial relations at the end of life - including being decidedly ambivalent about providing care in certain cases - lead us to some broader sociological questions that tie the moral ambivalence experienced by informal carers to these broader cultural and economic changes. If informal care is traditionally understood as part cost/benefit calculation and part normative imperative, are current sociocultural and economic circumstances tipping the balance toward withdrawing it, and what are the implications? As life expectancies rise alongside the incidence of chronic disease, it is important to consider how the demand for *long-term* informal care arrangements interacts with dynamics of compassion fatigue and the hopeful anticipation of death. Our participants often struggled to reconcile their own hopeful anticipation of death with normative prescriptions of 'a good death' and 'caring well'. Given these results, how might this tension be exacerbated by contemporary social change and the increasing precariousness of informal care? Informal care, some would argue, is an increasingly precarious 'commodity' (cf. Benería, 2008). In turn, the practice of informal care at the end of life in OECD contexts takes place amidst steadily retracting welfare states, economic tightening, and other challenges to family and community life (e.g. Bailey and Robertson, 2015). Full market participation often precludes informal care commitments which, in turn, creates a double burden on carers and no doubt contributes to the tensions and moral ambivalence carers experience. Carers may want death to come quickly for a variety of reasons - but with the heightened precariousness of informal care, they may also *need* death to come quickly in order to return to their various other roles in social life. The consequences of these dynamics for the experience of informal carers are an important implication of this study.

We have argued for a more nuanced and ultimately contradictory understanding of the dynamics of informal care at the end of life. As we have highlighted in the discussion here, it is important to contextualise the lived experience of informal care not only within individual psychology or the dynamics of interpersonal relations, but also within the broader cultural, socioeconomic and moral landscape including changing family structures, economic austerity, ideas about caring well, the good death, moral virtue etc. In presenting a critical analysis of informal care at the end of life, we hope to have challenged some of the normative understandings of end of life care that are complicit in producing the moral ambivalence, shame and suffering experienced by informal carers.

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