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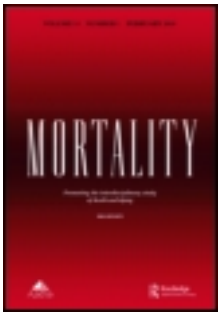

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Thinking beyond rupture: continuity and relationality in everyday illness and dying experience

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Thinking beyond rupture: continuity and relationality in everyday illness and dying experience

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ABSTRACT *This article challenges the dominance of a rupture model for understanding how we live day-to-day with life-threatening illness and the prospect of death. It argues that this model acts as a key interpretive framework for understanding dying and its related experiences. As a result, a rupture model upholds a normative and inherently crisis-based view of severe ill-health that reifies dying as an experience which exists outside of, and somehow transformatively beyond, everyday matters of ordinary life. These matters include the minutiae of daily experience which inform and shape our lived identities – as individuals and as relational selves. Drawing primarily on interview data from two family case studies that have contributed to an ethnographic project exploring family experiences of living with life-threatening illness, it will show how mundane, daily life is integral to understanding the ways in which families are produced and able to maintain a sense of continuity during circumstances of impending death. The analysis presented here moves analytical understanding of dying experience towards a theory of how individuals and families 'know' and engage with so-called 'big' life events and experiences. In this way, my study helps generate a novel and more inclusive way of understanding living with life-threatening/limiting illness.*

KEYWORDS: families; relationships; everyday life; life-threatening illness; dying; identity

A familiar story … Death: crisis, fear and rupture

Writing about the interdisciplinary study of dying, Kellehear (2009) argues that there is a great deal which the current knowledge base cannot tell us about dying experiences. He points out that the diversity of dying has been obscured by a problems-based research tradition, often rooted in medical, health and care concerns (2009, p. 1). This article will argue that the pervasiveness of this way of thinking about dying experience has been achieved in part through the dominance of 'ruptural' thinking. It begins by providing some examples of how rupture-related thinking works and these then act as important contextual background for the empirically based arguments that follow.

It is acknowledged that how a society approaches death and cares for its dying is 'a measure of society as a whole' (Department of Health, 2008, p. 10), and a reflection of its humanity (Kellehear, 2007; Kubler-Ross, 1969; Seale,

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2004). Often the experience of dying is ascribed a sense of 'bigness' which interlaces with the perception of death as an ultimate, emotional and extraordinary experience (see Foster, 2007). Such notions have influence in practice arenas, where theoretical models and ideas which inform counselling or support services in the area of dying and bereavement generally associate these experiences with emotional challenges and difficulties. For instance, seminal work in the area (Kubler-Ross, 1969; Parkes, 1975; Worden, 1982) focuses on the idea of emotional 'work' to be done, stages to be passed through or tasks to be completed with the aim of recovering emotional stability. Studies undertaken with professionals, who support the bereaved (Anderson, 2001; Arnason, 2001; Hockey, 1993), also reveal the centrality of a need to regulate death-related emotions, and a professional view of emotions as dangerous and disruptive forces requiring careful management. These examples suggest that conceptualising death as an extraordinary event that brings about intense and extreme emotional experiences is resonant in both popular culture and clinical and professional approaches.

Moreover, we often see similar crisis-focused themes in academic literature. About death's existential challenges, Becker argues that the universal 'terror' of dying is a psychological and emotional response so 'all-consuming' that individual psyches deny the prospect of it to enable humans to continue to live day-to-day (1973/2004, p. 25). Similarly, the following account by Berger and Berger (1976) presents death as an event that is marginalised in dramatic, fearful and mysterious ways:

> It is possible to conceive of human experience as being divided into a day side and a night side … The night side contains experiences that are uncanny, sometimes terrifying, and which put in question the firm reality of everyday life … The human experience most obviously belonging to this night side is the experience of death – which not only terminates the world of everyday life for whomever passes through it but which, for those who are witnesses of the death of another, appears as the ultimate threat to whatever is firm and lucid in everyday life. (1976, p. 354)

This dualistic conceptualisation of death as something other from the everyday resounds in sociological accounts which describe it as the ultimate threat to social stability and life's meaningfulness (see Bauman, 1992; Berger, 1969). In an attempt to minimise the threat of disruption or rupture to social life, modern societies are often understood to be death-denying (Aries, 1976, 1981/1993) and to consider death as a taboo subject (Gorer, 1965). This is further evident in the influential argument that death is sequestered in modern societies (Elias, 1985; Giddens, 1991; Mellor & Shilling, 1993). It is a view which describes the *removal* of death and its associated experiences from sites of *everyday life* such as the family home, and into spaces associated with modernity – such as hospitals and funeral homes (a rupture or separation of sorts one might argue). Importantly, a quote from Aries clearly shows how a theoretical focus on the

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sequestration of death leads to the associated consideration of it as a dramatic 'other', located in the domain of the spectacular.

> In the modern period, death, despite the apparent continuity of themes and ritual, became challenged and was furtively pushed out of the world of familiar things … Thus death gradually assumed another form, both more distant and more dramatic, more full of tension. (1976, pp. 105–106)

Here, death is conceptually understood in terms of its distance from ordinary, everyday life, which can be described as:

> … a lived process of routinisation that all individuals experience. Certain tasks which at first appear awkward or strange … gradually become second nature to us over time. Conversely, the everyday lives of others can seem deeply alien to us, precisely because the quotidian is not an objectively given quality but a lived relationship. (Felski, 1999, p. 31)

Arguably, then, by thinking in predominantly ruptural or 'othering' terms about death, we come to assume that the lives of those who are facing death must be, as Felski suggests, 'deeply alien'. In sum, the popular and academic picture of dying which dominates present-day western thought is one that is semantically aligned with notions of *rupture, emotional crisis and fear* and which positions it ontologically within the realms of extraordinary, 'alien' experience. Whilst this body of work has provided an important conceptual lens to reflect the ruptural possibilities and existential challenges that knowledge of impending death and/or dying experience may involve, I argue that with this lens alone it becomes difficult to connect the experience of dying with a sense of the mundane. Critically, as a result, death and dying all too often appear to be something quite separate from the idea of 'having an everyday life'. It is the *pervasiveness of this assumption* which this article challenges by bringing the everyday experiences of families facing death to the fore. Nonetheless, it is important to acknowledge that death is undoubtedly at times both a challenging and an emotional experience, and that the possibility of experiences of rupture – be these relational, psychological, physical or existential – are not being denied[1]. However, what this work will demonstrate is that death's uncritical acceptance within crisis-focused terms is problematic because it obscures the full range of end-of-life experiences.

Relationality, identity and family practices

The implications of ruptural thinking become evident when we consider the idea of 'having an identity'. The prospect of 'losing' one's identity is often thought to be a negative, deeply problematic experience, synonymous with a sense of unbecoming, losing direction and a distancing from who one once was and often from other people. Conventional wisdom suggests there is usually a

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trigger, a reason or at least an explanation as to why someone's identity has undergone rupture or indeed erasure. One frequently cited circumstance is the onset of a life-threatening or degenerative condition; an experience which it is *assumed* will disrupt, transform or dissipate a person's identity. A key seminal concept in the sociology of health and illness literature falls into the 'illness-as-rupture' approach. Biographical disruption, a concept first used by Bury in 1982, represents the idea that developing a chronic illness is experienced as a disruption and it has been extremely influential in shaping important qualitative inquiry into illness experiences (Lawton, 2003; Pierret, 2003; Williams, 2000). Bury argued that the ill person's biography and their sense of self, is deeply altered by the onset of illness. It has since been suggested that following this profound disruption, the individual undertakes the task of putting their 'self' back together again by telling their illness story and re-negotiating a new identity and stable sense of self (see Mattingly, 1998 and Frank 1995). And so, 'narrative reconstruction' (Williams, 1984), is 'an attempt to reconstitute and repair ruptures between body, self, and world by linking up and interpreting different aspects of biography in order to realign present and past and self with society' (1984, p. 197). Not only does this approach stress the distinctiveness of the *individual* in forming an identity, it also assumes that identity is something fixed rather than a process – that it is both reified and stable before it is subject to fracture when a person learns they are seriously ill (Hockey, 2010). Whilst others have argued that a disruptive or ruptural model of chronic ill-health has empirical limitations (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004; Pound, Gompertz, & Ebrahim, 1998; Williams, 2000), Hockey (2010) notes that theoretical perspectives within sociology demonstrate the importance of relationships between people (face-to-face or imagined) for understanding identity (see Jenkins, 1996; Mason, 2008; Smart, 2007; Smart, Davies, Heaphy, & Mason, 2012). In other words, we cannot think about identity without taking account of *relationships* between people as they unfold over time (Hockey, 2010).

Writing about *identification*, Jenkins (1996) argues that identity is a dialectic process whereby significant others reflect back to individuals a sense of who they are. He believes that this is an essential part of understanding one's own identity and therefore affirms that identity is a dynamic and processual matter, rather than something which is fixed. Importantly, this insight challenges the idea of *rupture* and the assumption that illness will inevitably make someone feel that their experience has displaced who they are (Hockey, 2010). It complicates the 'repairing self' rupture model with a more fluid and complex involvement of *relationality*, a term Smart associates with the notion that 'individuals are constituted through their close kin ties … without both formative and on-going relationships we do not develop our own sense of personhood or even individuality' (2007, p. 46). However, to accept this relational complexity is not to deny that people might experience fundamental change in their sense of self when they face something as testing as a threat to their life (Hockey, 2010). Rather, as Hockey (2010) has identified, it is about recognising the fluidity of what

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came beforehand and, as this article will go on to demonstrate, it is about understanding what comes after this knowledge, – something which has rarely been empirically explored in everyday, relational terms.

Practices: 'doing' family, 'doing' dying

And so, it has been argued that relationships, identity and a sense of fluidity, as these are played out in everyday lives, are inextricably interlaced. Moreover, this approach also suggests that 'identity making' is both active and dynamic – it is actually something we perform and achieve alongside others. In other words, we *do* relational identity work. We might expect there to be limits within which the relational can operate to affirm identity. However, even in the case of relationships involving the deceased, this is not so apparent. Rather, evidence suggests that the maintenance of bonds can enable particular self-identities and relationships to be sustained or redefined even 'beyond' death and physical existence (Bradbury, 2001; Francis, Kellaher, & Neophytou, 2001; Gibson, 2008; Hallam, Hockey, & Howarth, 1999; Hockey, Kellaher, & Prendergast, 2007; Hockey, Penhale, & Sibley, 2001; Kellaher, Prendergast, & Hockey, 2005). Importantly, these empirical studies have focused on practices, rituals, habits and memories in materially and spatially grounded everyday life to understand bereavement experiences of a 'continuing bond' (Klass, Silverman, & Nickman, 1996) with a deceased person.

That said, whilst there have been a number of insightful studies about post-death practices which sustain relationships after death in bereavement, practices have rarely been used as a lens through which to view the time leading up to death and to understand how relationality and relational identity is negotiated and achieved between family members while the dying person is still alive. In response to this, the research discussed in this article sought to take a situated and practice-based approach to understanding the relationship between mundane everyday life, relationality, and experiences of severe illness and dying which have so far remained under-explored in the empirical and theoretical literature. As argued above, it is the hegemony of ruptural thinking which serves to obscure this area of inquiry.

To take an explicitly family-as-lived approach, Morgan's (1996) seminal work on family practices is central to the theoretical framework of this article. To escape constraints inherent within a static notion of *the* family, Morgan's concept of family practices is a theoretical description of the active construction of family life in everyday, diverse family contexts. However, more recently, the concept of family practices has been developed further to encompass the *interconnected* ways in which people *feel* and imagine themselves as related (Smart, 2007). Smart (2007) explores how thinking about and imagining relationships can create feelings of being embedded emotionally and materially in the lives of others, and she suggests that these more interior processes are *entwined* with family practices and the 'doing' of family. These conceptual ideas

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which suggest that 'family' is performed, imagined, felt, achieved, created and produced rather than simply 'is', underpin the theoretical contribution developed here.

The study

To explore family experiences of living with life-threatening illness, repeat, in-depth interviews were conducted with members of nine different families. The people who took part in the research lived in a town in the north of England which has an ethos and character that can be described as broadly working class. In many ways, most families interviewed appeared to be 'typically' working class in terms of their values and/or aspects of their biographies. They were also all white British. All the ill individuals involved in the interviews had a cancer diagnosis (in most cases prognosis was terminal). In each family, a patient attending a hospice day care service was recruited (via hospice staff) and asked to invite their family members to be involved in the research. In total, nine patients and 14 family members participated in the interviews which were carried out over a 12-month period. Where possible, by conducting repeat, sequential interviews, a more sustained picture of family life and not just a 'snapshot' was gained. Moreover, where it was viable, returning to re-interview families and to enquire about everyday life as it was actually happening, allowed for an engagement with feelings and experiences that were infused with a sense of immediacy.

During the same fieldwork year and over a period of seven months, participant observation was undertaken on a hospice inpatient ward where I performed the duties of an inpatient volunteer and participated in informal conversations with patients, their relatives and different staff members. Appropriate NHS ethical approval for the study was granted.

Although the research was not concerned with close examination of narrative form, it was informed by a thematic approach to narrative where there is still a sense of keeping the overall story in mind and having a strong case (or participant) centred commitment, despite looking for themes across the dataset (Riessma, 2008). Whilst the entire body of data was analysed using this approach, the arguments presented in this paper focus primarily on ideas that emerged from interview data. More specifically, to demonstrate how mundane, everyday family life can act as a 'lived' framework from within which families make sense of illness and death, two case studies will now be discussed.

Daily life for the Baker family

Whilst spending time with Malcolm Baker and his wife Tracey (aged 57 and 59, respectively), it became apparent that they were able to draw on aspects of their day-to-day lives to express how they understood their relationships with one another in the context of Malcolm's terminal illness. This work also

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revealed important aspects of relational identity-making as a process embedded in everyday life. Moreover, whilst Malcolm and Tracey were ultimately faced with a separation that would be forever, this article will argue that they focused and perhaps made sense of this bigger separation through more immediate separations in everyday life, as these were experienced in their sleep, eating and pottering routines.

The couple and their two children had been living for a long time with long-term chronic illness within the family, in addition to the diagnosis of Malcolm's leukaemia. Since the very first months of his marriage to Tracey 30 years ago, Malcolm had suffered serious and at times life-threatening illness, meaning that for long periods he was unable to work and experienced chronic tiredness which restricted aspects of daily living. The fact that Malcolm also had difficulties with his sleep pattern meant that the tiredness he experienced as a result of his condition and poor health was particularly problematic. Although the couple explained that Malcolm's capacity to prepare his own meals and to 'potter' around or pop out in the car varied, most often Tracey was responsible for running their home, for preparing meals and generally looking after Malcolm's welfare. She was in charge of Malcolm's medication routine and dealt with family budgeting matters. Generally, the family had traditional ideas about 'family' and the fact that daily life did not always mirror these seemed to be the result of Malcolm's illness, rather than choice.

And so, whilst the illness experience was nothing new to the Baker family, they did concede that the life-limiting nature of Malcolm's cancer meant something qualitatively different from previous illness occasions. Time, especially after his initial diagnosis, had begun to feel finite. They considered themselves to manage nonetheless, and stated frequently how their Christian beliefs were of paramount importance in how they dealt with the illness and life generally. Interestingly, at times, they referred to this in rather mundane ways, stating that God was simply a part of their everyday lives and existential matters such as going to heaven (as they all believed Malcolm would) was something they considered alongside daily concerns such as trusting in God that Malcolm would be safe whilst out in the car. Even so, the family did worry at times, when Malcolm was out by himself. The importance of relational time and structure – of being expected home at a certain time and being acutely aware of each other's movements in space – indicated concern about Malcolm's fragile health, but it also reflected a wider preoccupation with routine and predictability which was integral to their account of daily life. As Malcolm explained:

> Malcolm: But I think when you are poorly this, this routine business is er you know its lord and master almost of your life (pause) … I think when you are poorly it does and your medication and your sleep and your meals and everything else it does govern your life … and it's difficult for Tracey because Tracey has to fit into that routine whereas other times she sort of 'oh ok you know it's whatever time it is, I'll go up … and do the shopping and I'll have a late lunch' you know – which you do sometimes.

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Tracey: Hmmm.

Malcolm: You go sometimes.

Tracey: But that causes you a problem then, doesn't it, cos you are thinking I should have had my lunch before this and

Malcolm: Well it can do erm, it can do.

Tracey: It does – you don't like it do you?

Malcolm: No I don't like it.

Tracey: No.

Malcolm: I've got to this stage where I am in this routine and I like me dinner about one-ish or twelve, one-ish whatever – erm but like you the other day … I didn't get back – that's right I'd been to the church and then I'd gone looking for this printer thingy stuff and … there'd been this accident so it was about half past three when I got in and you'd only just finished your dinner and erm about an hour later I'm sort of pottering around looking and moving pots and pans cos I want me tea (Tracey laughs). 'I've only just had my dinner' (imitating Tracey).

Malcolm's very rigid sense of mealtimes was, on occasions, in tension (and also a muted source of tension as the previous exchange between the couple intimates) with Tracey's more fluid routine. This marked-out and reinforced an awareness of separation between the couple that was understood by Malcolm in this instance through his reshuffling of pots and pans to accommodate the two different schedules. The way he describes the dynamic between the two of them suggests he was moving items around the kitchen and 'looking' and 'pottering' as a way of hinting at and asserting his own 'clock time'. The indirect way he appears to imply he went about this infers, as Tracey states above, that it can be a 'problem' when one routine clashes with another.

This notion of discord between the couple and a need to negotiate each other's daily movements was a recurring theme throughout their interviews. Bedtimes were a key focus for Tracey, where Malcolm's pervasive tiredness and the routine this necessitated 'mixed up' their whole life more generally. In one interview, Malcolm explained that he tends to sleep in short bursts and therefore goes to bed a few times throughout the day and evening, leaving Tracey alone for much of the time.

Tracey: You see your whole life is, is (pause) is mixed up with regard to his sleep …

Malcolm: I have problems sleeping … I have medication for it but I've had problems for donkey's years and the only way I can cope with it generally is

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the medication and a strict routine how it works for me … I am, some people are morning people and some people are evening people but I'm a morning person I'm awake … and then I wind down during the day and some of the other complaints that I have means that I can't eat much … so it has to be small and often … and I get just so sleepy its crazy. And that's how I am and I sort of up for me dinner and sometimes I go to bed after that but then up again and then (pause) go to bed for me tea and I have a couple of hours or so in bed … and then I get up and I come down and Tracey is off to bed (Malcolm and Tracey laugh). And I'm there watching TV 'til 1 o'clock, 2 o'clock in the morning until I can just feel myself going and then either sleep on the settee or whatever. The situation now is I'll get up onto that bed (double bed in the interview room), er so.

Tracey: Yeah I find it a bit lonely sometimes.

Talking about how this affected their relationship, they frequently referred to themselves as 'ships passing in the night'. However, Tracey seemed to express more overt regret and dissatisfaction with the situation, and Malcolm, despite at times conceding that routine could be a problem, made attempts to 'normalise' their discordant 'life clocks'.

Tracey: It is like caused a separation hasn't it … in that sense?

Malcolm: But some people live like that. I mean some husbands and wives they have different jobs different you know social things and erm they, they that's their lifestyle anyway.

Interviewer: But would you say that this style that you're in is because of the illness pretty much?

Tracey: I think so.

Malcolm: Oh yeah, yeah [it] wouldn't happen we'd be doing everything together – well practically we would still have our friends or whatever and still do things separately but it would be a life that we'd live together we'd have meals together, we'd have sleep together in the same room, probably go to bed at the same time. I don't know about that actually.

Tracey: What go to bed at the same time? (Laughs).

Malcolm: Well you have always been a late bird and I've always been an early. It was instilled.

Tracey: But don't you think though that it would have affected me if you were going to bed at half past ten then I would go to bed at half past ten if it was a proper carry on?

Malcolm: It might have been.

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In their conversation, here, it is clear that Malcolm and Tracey are reflecting on their own family practices, but they also suggest that there is such a thing as '*a proper carry on*' and they have an idea or a model of how couples *should* 'do' being a couple. In Gillis' (1996) words, they have an *idea* of family that they are living *by* and which is made meaningful via the identification that this is something different to the family they actually live *with*. Malcolm suggests that had it not been for his illness they would have conducted their lives in ways that more closely reflected the idea of 'proper' family life. The couple acknowledged here the difficulty they had sometimes in 'doing' what it takes to be 'a family' because of the illness.

Also on the subject of bedtimes, Tracey explained how recently Malcolm had been able to get up again in the evening and come downstairs for a while; and so to spend more time with him she had started to push her own bedtime back even further. Not only is this something which potentially helps close the gap between how they imagine themselves as a couple and what they consider a 'normal' family life, it is also an indication of Malcolm's increased 'wellness' and was therefore more generally significant for the family. In fact, over a period of about 10 months, Malcolm's cancer-related health had reached a plateau and actually seemed to steadily improve in some respects. This created a feeling of cautious hopefulness which was suppressed and moderated to ensure hopes were not falsely raised. More generally, the family's accounts of daily life revealed that they were required to negotiate *not* what they had anticipated would be a steadily progressing, linear deterioration in Malcolm's health, but periods of going up, going down and plateau. Talking more generally about how facets of their relationship – trust and reassurance – shift in line with ups and downs in the illness, the couple explain how decisions that make daily life happen become a site for negotiation which shapes their awareness and experience of the illness as a non-linear process.

> Tracey: … Erm since Malcolm's illness especially latterly, I've not found it as easy to trust his judgement as I did before.
>
> Malcolm: Hmmm.
>
> Tracey: Erm probably because of the illness (pause) that you because I know that you are not grasping things the same.
>
> Malcolm: No.
>
> Tracey: Or you are not erm you know understanding things and everything as well as you used to do because at one, I mean you were always very bright and capable and one of the things that really attracted me to him was the fact that he, you know he was erm straight and you sort of felt you could trust his judgement and erm you know er very (sighs) what can I say? (Pause) capable right ok, so it is more difficult when somebody's poorly like that to you know to trust that they have judged correctly – or grasped everything and so you tend to not be quite as erm … You tend to be a bit more wary of

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> his judgement and therefore and you know at one point I would not have questioned it and I'd have felt right he knows what he's doing that's it you know, but (laughs a little).
>
> Malcolm: … When you have sort of been ill and you've had to hand a lot of responsibility to someone else, to your wife shall we say and then perhaps you pick up and get better and you want to take those in to your own hands but your wife has learnt over the years over the long period that you've been ill how to handle these things herself and to make her own decisions then you have got a problem … it doesn't really matter you get there in the end but you can find that frustrating and I think I do sometimes find that frustrating that Tracey has got a will and whereas once she would have deferred to me she's 'oh I can sort this one out I know what I'm doing' (laughs) and I'll say, it's very much like that if we are sat in the car and we're deciding where to go (laughs) and which route to get and 'oh I know where' and I'm like 'oh that's not the way to do it' you know and then I've thought oh shut up and leave her alone.

It appears from these data that neither their daily life nor the illness were experienced by the family in static, linear or 'given' ways, but as shifting and fluid processes which required negotiation and gave mutual meaning to each other. As Kellehear (2009) has argued, although dying is often represented as a 'journey' or in terms of linear stages, many dying experiences are characterised by 'oscillation'. He writes:

> Dying, as an identity and as a physical experience, is not always an uninterrupted trajectory of decline. Dying can be, and often is, an intermittent experience determined by disease process and the social roles and circumstances that prevail in end-of-life situations. (2009, p. 8)

Notably, Kellehear mentions identity and social roles. Moreover, as was outlined at the outset of this article, what Kellehear is getting at here is that a dying identity (as with all identities) is something that is both inherently *relational* and *processual* (Jenkins, 1996). This is indeed something which resonates with how Malcolm's status within his family *vis a vis* his 'doing capacity' is changeable or oscillates, rather than irreversibly declining. In other words, his identity in this sense as an 'ill' person is not fixed and straightforwardly ruptured (Hockey, 2010). As the conversation between the couple indicates, Malcolm's status as 'doer' is one which finds meaning in relational terms as his abilities are monitored by those close to him and aspects of his identity are ascribed accordingly in the flow of daily life.

Ultimately, as this example shows, neither the illness process nor the family's everyday life could be separated out into discrete experiences; rather they give mutual meaning to each other. It can be argued that for this family, at times, what is considered to be momentous and existential – 'the big matter of death' – was lived through mundane material things and everyday routines. So, whilst Malcolm and Tracey were essentially faced with a separation that would be

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permanent, their accounts of daily life do suggest that they made some sense of this 'bigger' separation through more immediate separations in everyday life as these were experienced in their sleep, eating and pottering routines.

Daily life for the Kenny family

Jackie Kenny (68 years) also talked in great detail about the routine aspects of her daily life with husband Clive (74 years). Having enjoyed a few years of good health after her retirement and leading what she described as an active and healthy lifestyle, when I interviewed Jackie she was spending longer periods of time in her home due to pain and symptom-management problems related to her cancer. Despite at times feeling fed up with bouts of persistent pain and discomfort, Jackie was not at all resentful about her situation and explained that 'it wasn't such a bad existence'. She described how, since her diagnosis, Clive had practically 'taken over' the running of their home – something which she had been almost solely responsible for before. And so, in some respects, Jackie was able to view her cancer as having – in her words – 'some good come out of it', in the sense that it made Clive take more responsibility for their day-to-day living which she felt had in turn increased his confidence. Although Jackie's husband did not wish to take part in the interviews,[2] he was very welcoming and during Jackie's first interview he finished up the pots he had been washing in the kitchen and came into the sitting room to speak about how Jackie's health had deteriorated over the last couple of years.

Routine for Jackie did not seem to be such a problem, providing somewhat of a contrast to the Bakers. Yet whilst routine appeared to be experienced differently by the two couples, its importance in both cases was nonetheless evident. Jackie presented the routinisation of her life very much in terms of synchronicity – mundane tasks and exchanges which bound Clive and herself together into predictable actions and dialogue. The changes to daily life necessitated by her illness seemed to have brought the 'life clocks' of the couple closer. Jackie appeared to find the fact that her life was so carefully patterned somewhat amusing and she laughed about the intricate ways in which the husband she used to 'carry about' and do everything for, now anticipated and was aware of her most mundane needs. She could describe a typical day at length:

> Jackie: Well we normally have breakfast … about quart' to 10 as I say we get up and then Clive fetches the paper first and er I go in the kitchen … while he goes to the shop. What he does he has porridge Clive every (laughs) every morning he has porridge and I usually have some cereals of some description and I tend to have some Figs. or some prunes or some All-Bran … well they are all kept in a cupboard in the kitchen which is a bit low down actually er and at one time I couldn't get, I couldn't get stuff out so there again he's got into the habit of getting it out so now you see he goes to the shop, he'll say 'I'm just going for the paper I've got stuff out' and he gets it all out ready all his things and the pan for his porridge and then I make it you see – by the

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time he comes back his porridge is ready but then he washes up after breakfast … and then at evening time well it's not very often I eat a proper dinner but Clive does … and he'll go in and he'll say to me like 'what we having?' and he'll get it out of the freezer whatever cos see he knows where everything is he's in charge, he's put everything away he knows where it all is, he'll get it out earlier in the day … and then he prepares it all but then I usually go in about quart to 5 and cook it which is nothing cos all I do is put the gas rings on … but as I say he'll say 'shout me if you want anything' and I sometimes shout 'can you just lift me this out of the oven or open me a tin' cos I find that hard opening tins hurts me er thing when you turn it, little jobs like that he'll come and do and then we have dinner and then he goes and washes up and think he makes another drink and that's when he brings me me (laughing) nightie and me bottle then at 8 o'clock.

Interviewer: Bedtime.

Jackie: He'll say 'what do you want taking up now?' and I have a flask with some fruit juice in (laughs) cos I'm always drying out so he takes the flask up (Interviewer laughs) bag of medicines I've got a plastic bag with all these tablets in – what else does he take up? I usually go.

Interviewer: Like you are going away for a fortnight!

Jackie: All me equipment and then he pulls me, he takes the bedspread off for me cos we have like quilted thing on it he takes that off he'll say 'I'll just put you the telly on' he switches telly on (laughs) he does everything for me.

Interviewer: It's funny how he knows just how you like things.

Jackie: I just get in bed like the queen and I lay there reading and then I usually I'm asleep when he comes up.

Here, Jackie paints a very detailed picture of predictable days and represents her role in daily life in passive ways – stating that Clive is 'in charge' and 'he does everything for me'; the cooking she does is 'nothing' and at the end of the day she 'just gets in bed'. Her description in the above does however also point to her role as an 'over-seer' in the day-to-day management of their life. She still has an eye on what is happening, as is implied by the enquiry it seems Clive routinely makes as to 'what we having?', when they are preparing for their evening meal. In this exchange the historical pattern of Jackie and Clive's relationship seems to find an opportunity to be reproduced through the mundane medium of food. The fact that Jackie was able to so clearly recall minute details of the actions Clive undertakes to try and ensure that she is cared for, even assigning particular sets of words to him, also indicates the centrality of these routines to the family's engagement with the life-threatening illness of one of its members.

Interestingly, there did seem to be a sort of 'gentleman's agreement' between the couple which meant that certain aspects of daily life would be negotiated

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and accommodated with minimum fuss so the overall routine could persist, and family life would keep going. Clive's sensitivity and pragmatic approach to an embarrassing continence problem Jackie experienced as part of her disease progression was something that she was extremely grateful for. Talking about how Clive took up the practice of 'doing' Jackie's body work as a concern of his own and thereby making it into a process of negotiating relationality, Jackie explained how they managed the disposal of soiled pads, an action that was anchored in everyday considerations.

> Jackie: You see there again he's been ever so good really Clive I mean I know he's my husband he's a rights to be but he just says, at first I kept wrapping em in a carrier bag and tying em up in another carrier bag and if it was in the middle of the night I'd just leave it in the bathroom down at the side of the linen bin … and then in a morning he'd got up you see and he'd just say 'I've took that bag, I've put it in the bin' you know and like done it right you know as if it were a normal thing that you'd be doing …

Jackie went on to explain that Clive thought of alternative ways to dispose of the pads in bins away from the couple's home, and that he just took the matter in his stride, building it into his day-to-day routine. Whilst Jackie accepts that husbands should be '*good*' to their wives, ('he's my husband he's a rights to be'), this particular task was considered beyond the usual realms of expectation and obligation – it was especially demonstrative of the 'quality' of their relationship, and therefore noteworthy. As this example shows, with this couple there was an intimate closeness brought about by the shift in general 'doing' roles necessitated by Jackie's illness. This was not an intimacy of overt emotional expression and dialogue, but one which was constituted by, experienced as, and understood in relation to, the performance of mundane tasks in daily life (see Christensen, Hockey, & James, 2001). On occasions, Jackie did mention Clive's tendency to rarely speak about his feelings and there was a hint, perhaps, that she might have welcomed a more explicit emotional dialogue between the two of them. However, she accepted Clive as that 'kind of man' and said she knew he cared 'by what he does'. Jamieson (1998) challenges the idea that 'disclosing intimacy' – an overt, spoken and shared concern with declaring inner feelings between significant others – is the only true form of 'doing' intimacy. On the contra, she imagines a rather more 'silent intimacy' where 'affection for and feelings of closeness to another person are not necessarily accompanied by a dialogue of mutual disclosure' (1998, p. 8). As Jackie explained in response to my question about how the illness had affected her relationship, certain 'silences' were important:

> Jackie: Er I don't know how to say it really its (sighs) its, its, Clive's wanting to do I don't know whether he's like wanting to compensate or he feels sorry and he, he can't show that he does, he doesn't show his emotions – very rarely – but he's wanting to do, do, doing all the time everything I do 'let me do it, let me do it' that's how it's affected us so he's just taken over

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> actually running the house he just – well he does do everything. Occasionally I'll – and I don't let him know I've done it (laughs) cos he's a love – I just sometimes if he's gone out I get iron out and I just iron cos he might have just ironed a blouse or something that's you know and he's left a big crease right where it shows but I don't say anything. So I just wait and.
>
> Interviewer: Until he's gone.

Highlighting the relational dimensions of emotionality which are clearly evident in Jackie's account, Lupton argues that emotion is 'an intersubjective rather than an individual phenomenon, constituted in the relations between people' (1998, p. 16). Therefore, the circumstances of people's everyday lives, as they are lived, are central in understanding how emotions related to facing the prospect of death within a family are negotiated and emerge as a dynamic process within specific histories of relational contexts and practices. Thus, family practices are a key site for understanding how emotionality operates between Jackie and Clive; although they appear to be 'hiding' or not openly disclosing their emotions, the couple are 'doing' intimacy in other important ways via the negotiation of family practices. As Jackie stresses, in the above extract, Clive became completely fixated with 'doing' things for her and she felt that this was his way of expressing his emotions related to the difficult transitions they were facing. Reciprocating this, Jackie also engaged in her own small 'silences' – a form of emotion work – and she talks here about performing 'corrective' tasks in secret to ensure that Clive's care efforts are not undermined. If, as Jackie suspected, Clive was investing his emotions in his performance of daily tasks, making sure that he did not realise that his ironing was not always 'up to scratch' was important so as not to communicate through the act of re-ironing, an undoing of sorts, of the emotional investment Clive had made. What might seem like 'small' details about this couple's daily life can actually give a rich insight into the ways in which they negotiated the constraints of Jackie's disease and how it affected their relationship and who they each were within it. Jackie strives to look after Clive's emotional well-being by 'doing' emotion work, something which she had perhaps always done when she was more able to undertake practical 'doing' tasks such as dealing with household matters which Clive was less confident at managing.

The accounts of family practices in these data thus enable a nuanced understanding of how continuity is negotiated and sustained by the Bakers and the Kennys and the relationships that produce their families. As the data show, they are not denying the bodily changes that one family member is undergoing, nor their implications; rather, their mode of engagement with these changes helps constitute their knowledge of what is unfolding and to come. To reiterate, the argument made in this article is similarly *not* about denying that dying can at times be a difficult experience (there were occasions during the fieldwork when this was apparent). What it aims to show is that a sense of continuity, a belief in pragmatism and an immersion within mundane matters of the

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everyday were important to families facing life-threatening illness. And therefore, what it has argued is that paying analytical attention to these everyday ways of engaging with severe ill-health and dying challenges the *theoretical generalisation* of death-related experiences in predominantly crisis or rupture-related terms.

Conclusion: the everyday of dying: 'knowing' and lived experience

Exploring dying as a form of *everyday* experience is a step in the direction of expanding the scant knowledge base that exists to help us understand dying as a social, *relational* process (Kellehear, 2008, 2009). In the family case studies presented here, matters of mundane, everyday life feature heavily and are important for gaining a multifaceted picture of family experiences and relational identity. However, as has been discussed throughout, theoretical focus to date has centred largely upon how life-threatening illness challenges the idea of an everyday, because facing death is generally associated with the production of rupture, crisis and disruption. This association, then, suggests that everything about the everyday becomes unpredictable, transformed and changed. Yet, returning to the work of Felski (1999) introduced earlier, it is possible to consider how everyday life is both fluid and processual. In other words, according to Felski, the everyday shifts and is subjectively *lived* (produced) as a meaningful experience for individuals; 'the quotidian is not an objectively given quality but a lived relationship' (1999, p. 31). Importantly, due to the inherently emergent quality of everyday life, she suggests that 'it makes more sense to think of the everyday as a way of experiencing the world rather than as a circumscribed set of activities within the world' (1999, p. 31). When considering the families discussed in this article, and for whom the life worlds of severe ill-health and/or dying shaped their experiences of daily life, it should also be recognised that due to the subjective, relational nature of the everyday this is not something external or separate from the experience of living with and facing death. Rather, the above case studies have shown, it is through and *within* their experience of the everyday and its mundane practices that families come to make sense of and *know* their world of severe ill-health and dying. In other words the experience of one constitutes and makes sense of the experience of the other.

Therefore, in thinking about the everyday lives of these families as lived experience (Felski, 1999), this article has shown how mundane, daily life is integral to understanding the ways in which families and relational identities are produced and continue, during circumstances of life-threatening illness and impending death. In this sense, it represents an important challenge to the dominance of ruptural and crisis-based models of identity and death-related experiences by opening up conceptual space within which to explore the more everyday aspects of these experiences.

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Notes

[1] Moreover, it is important not to lose sight of the diversity of dying experiences. For instance, in sudden and unexpected deaths, the rupture/crisis model may be more generally applicable to people's experiences.

[2] Jackie also had two adult children who were unable to take part in the study. However, during interviews Jackie reflected on her relationships with them and talked about her sense of how the illness had affected them both.

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