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Living on the margin: understanding the experience of living and dying with frailty in old age

Within policy and practice there is an increasing interest in the care of frail elders. However understanding of the experience and challenges of living and dying with frailty in older age is currently undeveloped. Frailty is often used as a synonym for the increasing infirmities that accompany ageing and the slow dwindling dying trajectory of many elders. However, there is little empirical work on the experience of being frail to inform social gerontological perspectives and welfare provision. Through analysis of repeated in-depth interviews over 17 months with 17 frail elders living at home, key factors that shape elders' experience of being frail emerged. The study argues that the visible markers of functional limitations and the increasing social losses of old age bring finitude to the fore. To retain anchorage in this state of imbalance, frail elders work actively to develop and sustain connections to their physical environment, routines and social networks. This experience can be conceptualised as persistent liminality; a state of imbalance "betwixt and between" active living and clinically recognised dying. This paper highlights the precarious and often protracted dying trajectory of frail older people. Whilst it could be argued that developing into death in older age is part of a normal and successful course after a life long-lived, recognition of and support for older people deemed frail is lacking. Frail elders find themselves living in the margin between the Third and Fourth Age with little recognition of or support for the work of living and dying over time. This experience of frailty contests dominant cultural and welfare

practices and policy frameworks that operate in binary modes: social or health; independent or dependent; living or dying.

Research highlights

- Frailty in older age is a period “betwixt and between” active living and clinically recognised dying.
- Older frail people actively engage in the work of creating and sustaining connections to manage their uncertain, and possibly protracted, dying trajectory.
- Accumulated losses, including loss of social networks, militate against connection with health and social care services.
- Older frail people’s experience between the Third and Fourth Age can be conceptualised as persistent liminality.

Key words

- Frailty
- Older People
- Living and Dying
- Persistent Liminality
- Fourth Age

Background

Successful identities of ageing are often related to the Third Age (Laslett, 1989); conceptualised as a time of extended consumerism, opportunity and activity in later life. Rowe and Kahn (1998, p433) suggest that successful older adults are those who demonstrate a low probability of disease and disease-related disability, high cognitive and physical functional capacity and a continued active engagement with life. Similarly, Baltes and Baltes (1990) equate optimal ageing with adaptation to the physical and social vulnerabilities of old age. However, in later writings these authors suggest the losses of late old age or the Fourth Age (at approximately aged 85 and over) become increasingly difficult to adjust to; *‘Living longer seems to be a major risk factor for human dignity’* (Baltes & Smith, 2002, p3). This social construction of the Fourth Age as a loss of agency and bodily self-control is often linked to frailty. Frailty is therefore frequently conceptualised as an antonym for successful ageing (Richardson, Karunanathan, & Bergman, 2011) a separating practice and a central term for those limiting conditions of the (ageing) body (Gilleard & Higgs, 2010a).

The social gerontological literature suggests that constructs of frailty are diverse. Gilleard and Higgs (2010b) posit that culturally those deemed frail have few self-empowering narratives. They argue that frailty is held within a social imaginary as a black hole, a socially void space into which older people are sequestered away to decay and die. Thus within a social imaginary frailty, like a black hole, is both unknowable and a space from which there is no return.

Hockey and James (2003) argue that social identities in late old age can be conceptualised as liminal. Liminality (after Turner (1974)) is a threshold space, a transitional point between social structures. Such spaces are fluid, allow for the potential redefinition of self-identity and can even be a position of power. Thus although older 'liminal' individuals are placed in an uncertain outsider status this social positioning can provide a space from which "weak" elders exert power. The vulnerability of old age can expose the very decline and dependency from which wider society seeks to distance itself. Thus identities are not fixed nor necessarily related to dominant understandings of a declining body. Grenier (2006b, 2007) develops this thesis in her work on the subjective experience of older frail people. She and others (Becker, 1994; Kaufman, 1994) argue that frail elders themselves differentiate between being and feeling frail. The label of frailty is actively resisted as elders distinguish between the body one is (self-identity) and the body one has - a physical, vulnerable, and objectified social identity.

Within Western welfare policy and practice frailty is increasingly used as a means of classification, to prioritise and fund care. Indeed, clinically frailty is often used as a synonym for the slow dwindling dying trajectory of many older people (Lynn. & Adamson., 2003; Markle Reid & Browne, 2003). This trajectory is gradual and unpredictable, encompassing accumulated and multiple health problems which at some point tips the person into the dying phase. The drawn out, uncertain and dwindling process of dying with frailty is arguably at odds with dominant health and social care practices. Welfare provision separates people into either living *or* dying in order to determine care needs. An important but relatively small gerontological literature argues

that this binary classification is unhelpful and misses the significance of older people's experience of accumulated loss (Holman, Meyer, & Cotter, 2004; Lloyd & Cameron, 2005). The links between dying and frailty in old age require much greater substantiation and development. However, there is little research into the experience of elders labelled frail.

This paper draws on findings from a longitudinal study of the subjective experience of being a frail older person living at home. The aim of the study was to understand the experience of home-dwelling older people living with frailty over time in order to develop the empirical evidence base for this group and to consider more fully how narratives of frailty can shape person-centred care provision.

Methods

To capture the dimensions of social, psychological and physical frailty, the research design used a combined qualitative psychosocial method. Psychosocial research conceptualises experience as a constant and dynamic communication between internal psychological and external sociological dimensions manifest through unconscious or feeling states, and conscious communication (Hollway, 2004; Roseneil, 2006). Thus, data collection and analysis takes account of emotions felt as well as words spoken.

Sample

Frail older people were identified through an older persons' intermediate care team comprising community nurses, speech therapists, physiotherapists, occupational

therapists, care support workers and a geriatrician. These U.K. multidisciplinary teams work across domiciliary and community facilities to provide intensive support at times of particular vulnerability and to prevent or minimize hospitalisation. Frail, community-dwelling elders were defined by the team as people of advancing age, unable to carry out independent activities of daily living (Lawton & Brody, 1969) and considered to be vulnerable to physical decline. Nineteen older people were purposively selected for potential inclusion in the study, as they lived at home and were regarded by the intermediate care team members as being frail. Two people declined to participate after being informed of the study and its aims; one because English was not their first language and the other because of rapidly deteriorating health. Five men and 12 women, aged 86-102 at the time of recruitment, were therefore included in the study. Thirteen participants were widowed, one separated and the remaining four married. Nine frail elders lived alone, three shared a house with their children, four lived with their spouse and one lived in community sheltered housing. All had some contact with health and social care services, ranging from intermittent contact to daily involvement. People with a diagnosis of dementia were excluded from joining the study although the study design and ethical procedures took account of cognitive deterioration over time.

Over the course of 17 months (October 2006-March 2008) the participants were repeatedly interviewed, up to four times, in their homes by the principal researcher (CN). The temporal nature of experience was an important element in capturing the complexity of changing states of vulnerability and hitherto an under-researched aspect of living with frailty. The study gained ethical approval from Ealing and West London Mental Health

Trust. All participants received written and verbal information about the study and informed consent was confirmed at each cycle of data collection. All were assured of confidentiality and that pseudonyms would be used in all research reports.

Data collection

Two psychosocial narrative approaches; the Biographic Narrative Interpretative Method (BNIM), - (Wengraf, 2001; Wengraf & Chamberlayne, 2006) and Free Association Narrative Interview Method (FANIM, (Hollway & Jefferson, 2000) were used to elicit narratives of frailty over time. These two approaches recognise that life history frames experience and that the way people tell their story is not random; it follows a general pattern, based on cultural and personal history. Both methods use open questions and pay close attention to the ordering and phrasing of the narrative. BNIM is a highly structured and staged method of interviewing and analysis. Narratives are collected through a two-staged face-to-face process. In Stage One the interviewer offers a single opening question to support rather than direct the content and telling of a story. The question in this study was *“Having reached the age that you are please would you tell me the story of your life as an older person, all the recent events and experiences that are important to you personally? Please take the time that you need”*. Once the question is spoken the researcher listens but does not interrupt. Stage Two allows for the interviewer to go back and ask more detail about a particular experience but only in the order in which it was raised, using the language of the participant. Interviews are audio recorded, transcribed and subject to a staged analytical process. Within the study BNIM was the method of choice but for some interviews it was difficult to adhere to. This was primarily due to

participants' frailty meaning they became cognitively tired and needed prompts to recall their thoughts. In this case the more participative, conversational approach of FANIM was used.

Field notes were informed by psycho-dynamic observation techniques (Bick, 1964). This is a method of reflecting on the participants' and researcher's emotions and their possible meanings communicated within the interview. Psychodynamic theory posits that experiences are infused with meaning; these 'immaterial facts' (Caper, 1988) are beneath and around what we are immediately aware of but are communicated through the feelings engendered when encountering another. Psychoanalytic observation is a structured way of recognizing and interpreting these feelings by observing, recording and with a wider group, using psychodynamic theory to understand the emotional experience of the encounter. For example, the concept of projection (a defense that involves locating a feeling or part of the self in another in order to gain relief from the feeling) underpinned the field note analysis of Hetty detailed on Page 12 of this paper.¹

Four participants (two individuals and one couple interviewed jointly) were subject to four rounds of interviews and detailed in-depth case analysis. These three 'gold cases' were chosen after the first round of interviews, because they were indicative of three different points of gradations of physical frailty: intermittent dependency and

¹ (Further details can be found in (Nicholson, 2009).

independence (Joan's narrative); continuing stable housebound dependence (Alfred and Elsie's narratives); and highly escalating morbidity (Eli's narrative).

Data analysis

A modified BNIM analysis was used which combined the staged interpretative process of BNIM with data collected through psychodynamic observation. The BNIM analytical process has a common base with grounded theory (Glaser & Strauss, 1967) in using analytical steps of extraction, hypothesis generation and testing data. However, within BNIM the connection between the lived life and the told story of each participant is retained for as long as possible; thematic extraction from the participant's data is performed later in order to keep the data 'whole' for as long as possible. The three in-depth whole life 'gold cases' were constructed and subjected to cross-case analysis. Emergent themes were compared and contrasted against data from the remaining 13 participants using an iterative and recursive process of syncretistic perception (Froggett, 2007; Froggett & Hollway, 2010), similar to Borkan's (1999) immersion/crystallization method of qualitative data analysis, which cyclically alternates periods of intense engagement with the data with periods of researcher reflection, yet includes attentiveness to emotional communications within the data. The researcher's (CN's) analysis and interpretations were validated by a psychodynamic observation group involving psychodynamically trained practitioners, one-to-one supervision and a reflecting panel at the point of cross-case analysis. This reflecting panel met over the course of one day, with two written communications over the subsequent two months and intentionally brought together academics and clinicians from social science, gerontology and anthropological

backgrounds to test the analysis and strengthen or weaken interpretations of emergent themes.

Findings

In detailing the experience of frailty in older age it is important to note that nobody in the study used the term ‘frail’ to describe themselves or their situation. Indeed frail older people living at home are the survivors, outliving the majority of their birth cohort, and living outside institutional care. These are important considerations in stories where resilience and capacity were evidenced as well as the difficulties of an increasingly unreliable physical body. Protracted or ‘dwindling’ dying was demonstrated through participants having multiple and accumulating health needs and becoming increasingly dependent and frail as the study progressed (9 participants reported unplanned hospital admissions). However, only one participant, Eli, had died 8 months after completion of data collection, aged 103.

Three main themes arose from the analysis. *The dynamics of physical and psychosocial frailty* details the persistent state of uncertainty and loss experienced as a result of progressive physical and psychosocial changes. *Sustaining connections within the home* presents the work that older people engaged in to remain anchored within the imbalances of their frailty. *Connecting with death and dying* addresses these older people’s work of acknowledging and communicating finitude within frailty.

The dynamics of physical and psychosocial frailty

The losses of physical capacity through frailty brought in a new or heightened sense of change; both in terms of how participants saw themselves and in relation to how others saw them. This experience was for some a gradual decline and for others a sudden and shocking rupture which they related to a specific event, for example a fall. Florence, aged 87, articulated this sense of ‘before’ and ‘after’:

You think you're going to go on the same way, at least I think most people do, don't they? I never thought one day I should be sitting here, can't do anything - never even thought of it. Well, until I fell over that day.

Physical incapacity was a constant reminder that life was no longer what it had been. Thus the stories of loss of bodily function were also the stories of living with the loss of whom and how one is in the world. Hetty, aged 87 years, narrated her experience of loss of physical capability through increasing arthritis, falling and muscle weakness, evoking her anger and resistance. Her first interview began by recounting the rage that she felt towards her family, friends and people she met who she felt treated her differently because of her diminishing physical capability. Her narration detailed the considerable physical activities she engaged in, including theatre trips and gardening, and she presented herself as lively in both body and mind. However, the second interview, six months later, was more nuanced. Towards the end Hetty noted:

My hearing's getting very bad. It's no use buying another one [hearing aid]. I've bought two and none of them doing any good at all - useless. So I don't

know really. I've got tinnitus in both ears, which doesn't help. ...I don't know really. I get these rotten spots now come up. I can still only get my hand up this high, I can't do my hair. ...And I'm losing it, what little I've got, I'm losing.... Oh I don't know really.

Within Hetty's narrative there was a bridging between continuing to be lively and presenting herself within the interviews as such, and the acknowledgment of her frailty. This was difficult and tentative work. Hetty's repeated phrase '*I do not know really*' was an uncertainty the researcher experienced whilst being with her; the researcher felt like *she* took up Hetty's ambiguity and was unsure how to proceed:

Hetty asked if I'd like a cup of tea and I said 'Yes please' and I felt like it was immediately the wrong response, because there was like 'tut tut' and then 'Oh okay'. I felt like I should have said no and I tried to retract the request. This was met with rolled eyes and a comment about making up your mind... And I felt that sort of slightly wrong-footedness throughout the whole interview.
(Field notes, 1st interview)

The losses and meanings made of being physically "wrong footed" seemed to evoke in some participants great emotional pain, as though their whole self was imbalanced. Pat, aged 98, talked of the loss of not being able to go outside as '*so terrible*' for, '*that's when I feel alive*'. Within frailty, getting back on one's feet seemed more than a physical mechanical act, and re-balancing of one's self was hard work. Florence, 87, had to use a

walking frame to mobilise. She noted that she was brought up to be independent and always on the move, and found her immobility *'intolerable'*. Within her narration she repeatedly connected back to the past with the phrase *'I mean I didn't have to stop and think then'* when talking about her former ability to walk without assistance. Her narration involved angry exchanges with her son who urged her to walk and she retorted:

Well, I'm trying with that, [the frame], I still don't like it. At 87 it's a job learning new things - if you ever get to 87.

Florence seemed to struggle to allow herself to feel dependent and accept appropriate aids to mobilise. Rather she wanted to stop walking, she slept as much as she was allowed, and talked of wanting to die. This was difficult for her son who kept waking her up and urging her to look to the future.

The findings suggest that physical frailty could lead to a psychosocial imbalance. A recurrent phrase in the narratives was *'a loss of confidence'*. Pat, aged 98, noted:

And first of all, I had a fall and broke my arm, and that seemed to upset the whole system. The pain from the arm wasn't too bad, but it seemed to upset me, I don't know, sort of... it's difficult to describe, but I was looking for trouble all the time... Things just seem different now.

For most participants, progressive frailty appeared to bring in a profound imbalance and a questioning as to the security and support that their changing social worlds could offer. The uncertainty of their unbalanced state precipitated both individual and familial unease. This uncertain marginal state in which the participants lived can be understood as persistent liminality; frailty in old age viewed through this lens is seen as a constant but changing space, which although marginal can afford a position of redefinition and critique (Hockey and James 2003). Others (Kelly, 2008; Little, Jordens, Paul, Montgomery, & Philipson, 1998) use the concept of persistent liminality to underpin the subjective experience of living with life-limiting illness. It is a state in which identity is continually negotiated through a prolonged dialectic between body and self. The findings from this study reveal the physical and psychological effort of living in a persistent 'betwixt and between' state. A significant part of this effort involved frail elders working at remaining secure within their immediate home environment and social networks, considered next.

Sustaining connections within the home

Being at home was important to participants because it brought feelings of control and anchorage to their lives. Within the imbalance of frailty, participants needed to accommodate the physical and social changes necessary to continue to 'be' at home, but equally needed to work to regain or reconfigure what it meant for them to 'feel' at home. Being at home was more than occupying a physically familiar space, it was also an anchorage to previously frequently habituated places. For example, Eli, aged 102, could no longer go out into his garden so his children hung flower-patterned paper panels on his

bedroom wall. As the study progressed his mobility decreased, and his bed and chair were moved to the front room, nearer the garden. He requested that the lounge curtains were never drawn, not even at night. Flora, aged 87, co-opted into her space the streetlight outside her house. She narrated how her daughter had repeatedly asked the Council to replace the damaged streetlight which illuminated Flora's room, enabling her to see, be seen and remain connected to the outside world:

For months I had no streetlight here. But my daughter faxed all my Councillors and at last, the Council came and put it up, I don't like it [the style] but still I've got a light and so I know I can see again and they can see me.

Sustaining connections to the past was given as a reason by participants for remaining in their homes. For example, Evelyn, aged 87, narrated the importance of her ornaments from around the world. However, her progressive physical dependency threatened her ability to stay in her own home. Relatives had urged her to reduce the 'clutter' in her home and to think about a retirement flat. Evelyn had refused. She felt that if she had to dispose of all her possessions and move into a smaller property she '*would be dead in two weeks.*' For Evelyn, and others, her possessions anchored her to her past life and relationships, which seemed to provide meaning and cohesion.

For most respondents, much of their daily work lay in maintaining and sustaining their place in their immediate world. Daily routines served to ground participants in the present

and in a wider continuity of social relations. Participants talked of holding off from a pleasurable activity until later in the day; Esther, aged 96, restricted her cup of tea until the afternoon, Jack, aged 86, did not read his newspaper until after he had had supper. Such delayed gratification may be about creating reference points, fixed knowns in a largely unstructured and, for some, long day. For those less physically active, routine remained important. Some participants wrote down daily experiences in a diary. Eli read his Bible twice a day; as his sight diminished, he recited favoured passages, and towards the end of his life his daughters maintained this routine by reading to him. Esther's daughter read her the newspaper each morning. Esther was going blind but spoke of the newspaper as '*getting you out of yourself, seeing the world again*'. Such routines served not only to fill a space but also connected participants to a past and a present, to the rhythm of work and rest practised in wider society.

For some, routine kept unwanted thoughts of dependency or decline at bay. Joan, aged 87, talked of putting on the television and reading books every day to '*get my mind back onto cheerful things*'. Several participants noted that switching on the television was the first thing they did on waking. Aged 87, Doreen's narrative detailed the vigilance of her everyday routines. Her story seemed to betray a fear of what might happen should she stop. Doreen saw the ceasing of routine as responsible for tipping her friend into dying:

I'd love to stay like this [in her chair where she felt most comfortable] - you've only got to start doing that. You see my friend; she started staying in the chair. And then it was staying in her dressing gown and she seemed to

just drop away then; that I sort of think to myself 'no, you mustn't do it; you've really got to keep on'. So I suppose I will, I'll just keep on as long as I can.

Social support itself grew increasingly frail as participants became more housebound and isolated. The experiences of participants suggest that the challenges of decreased physical and social mobility within frailty make social connections hard to sustain. Paradoxically, connections with welfare services seemed to exacerbate imbalance, despite these networks being necessary to maintain and assist elders in 'being frail'. Participants were unsure of when formal carers would come and daily routines were often disrupted. People struggled to accommodate carers who arrived to put them to bed too late or too early, or who failed to appreciate the significance of the timings of their day.

For all participants, being and feeling at home was only possible through the personal social networks they had developed and nurtured. Particularly for those living on their own, a network of neighbours and friends predominated over family to provide this daily social 'glue'. For example Joan, aged 87, immobile through a broken ankle, noted that it was her neighbour, visiting in her lunch breaks, who provided personalised care in the shape of much needed cups of tea. However, participants struggled with the increasingly diffuse geographical reach of family and neighbours. Pat, aged 98, lived on her own, was almost housebound and had no immediate family nearby.

Many participants narrated that friends were dying and neighbours had moved away, creating unfamiliar environments. There was a loss of known reference points; of being in and around places and people who were familiar. For Doreen, aged 87, as with Alfred, 86, and Jim, 91, this was articulated through distrust of *'foreigners'* and an increasing sense that *'it is not my country anymore.'*

These accumulating and progressive losses of frailty were vividly narrated within this study. As Grenier (2006a) observed, the rupture and loss that bodily decline brings can lead to an emotional sense of “feeling frail”. This embodied experience and its related meanings are forward looking. There is an accompanying fear of further decline, loss of independence and separation from society. Grenier argues that participants’ “inside stories” (the feelings associated with frailty) may act as a resistance to or avoidance of being identified as physically frail. Thus the emotional experience of frailty has a protective function. This study builds on Grenier’s thesis. It suggests that personal identities of frailty are constantly constructed through the work of maintaining routines, enabling elders to continue to construct identities alongside a frail body.

The emotional work of frailty is key to understanding the experience of being frail. Conceptualising frailty as persistent liminality draws attention to the ongoing processes of loss and separation inherent in being frail. The accumulation of loss creates ambiguity and transition both for the individual and the wider society in which they live. However, the significance of the losses of late old age is often denied in policy and practice (Lloyd & Cameron 2005); thus housebound and frail elders often fall outside a clearly defined

social and health need. Within the uncertain world of persistent liminality, frail older people have little support to manage and express emotion or care practices to help them manage their “living loss” (Kelly 2008). This loss of both feeling and being at home is managed by the creation of daily routines, which are worked at and refined to accommodate changing vulnerability. Through their narratives of accumulating and progressive losses, participants communicated explicitly and implicitly the challenges of living with an obviously circumscribed future, the final theme of this paper.

Connecting with death and dying

Participants connected to the future and their finitude throughout their narratives. The work of holding together loss and continuity within frailty in old age was contained within the wider context of the gradation into death. The visible markers of functional limitations and the increasing social losses of old age brought to the fore the understanding that life was coming to an end. Participants’ narratives were punctuated by phrases such as *‘it’s all downhill now,’ ‘it’s not going to get better now’* and *‘there is no future now.’*

In becoming frail, people begin obviously and consciously to inhabit the space between living and dying. Lillian, aged 91, encapsulated the experience of the changing transient state of frailty:

*We’re all getting older or dying. Everyone I talk to now, their friend has died
... we’re still standing but only just, andwho knows for how long?*

Some felt this movement into an *'old body'* through the response of welfare services. For example, Eli, aged 102, repeatedly narrated stories of being sent to an Emergency Department by an out of hours' medical service and discharged without any treatment:

At 8.00 pm a doctor comes. 'What's your age? Why have you come?' 'You should go home. You go'. I know what hospital means when you take the old there.... How am I supposed to... where should I go?'

Eli told this story in three of his four interviews with considerable sadness and bewilderment. His continual returning to this vignette suggests a profound discontinuity and a sense of abandonment. He experienced the hospital as a place where there was no knowing of how to care for his body or for him. The analysis of Eli's biographical data and story suggest that Eli's self-identity throughout his life was strongly linked to his acquisition and utilisation of knowledge. However, the uncertainties of dying in late old age, and arguably the binary 'living or dying' approach of the Emergency Department, seem to challenge both his knowledge and that of the professionals. Within the hospital, there seemed to be a difficulty of knowing how to respond to Eli's "frailing body". Eli returned to the Emergency Department three times during the study before a friend, who had prior experience of caring for a dying relative, mobilised Eli's referral to palliative care. He was with Eli at his death at home. Eli's narrative illustrated the difficulty, both individually and collectively, of knowing how to respond to a body that is wearing out over time. His repeated phrase *'the mind is wanting but the body is not able'* was

expressive of the challenge of bridging into the space of living whilst dying for many of the oldest old. The transition from ‘keeping going’ to ‘letting go’ appeared difficult to make particularly for this cohort whose resilience had perhaps kept them alive into late old age.

Penny, aged 86, and her husband Bob’s co-constructed narrative painfully revealed the difficulties of thinking about finitude. Bob, aged 85, continually expressed a desire to die and dissatisfaction with his now sedentary life. Penny in return was angry at his attitude and ambivalent about the burden of caring for Bob. In the following extract, while Bob had left the room, Penny expressed her anxiety about what might happen if she did not make Bob exercise:

And then he doesn't seem to be so strong - we got as far as nearly to the pillar box, you know round and round, and once we went right round in a circle, but I don't know, now he doesn't seem to want to go so far as that. I'm just terrified he's going to die... [Penny began to cry but stopped when Bob re-entered the room].

Bob’s dying was not mentioned again during their sole interview and field notes commented on the lack of support from both friends and formal services for Penny as she mourned. Similarly, Alfred, aged 86, and his wife Elsie, aged 87, did not discuss their own mortality during their first interview. However, during their second interview Alfred expressed a desire to die. He repeated this twice, yet the first time Elsie ignored

this turn in his narrative. Alfred returned to the theme later in the interview and noted, *You might as well, I won't say it... No I will,... be out of it.* 'Elsie responded by laughing and remarking that she wanted to live forever. However, in their fourth interview Elsie articulated her sadness of things unaccomplished in her life and her fear of either Alfred or herself dying before their son, who had learning difficulties and was dependent upon them.

The conversations about loss and a circumscribed future were different from the practicalities of choices around how to die but were concerned with the processes of living and dying over time. Death and dying was something to be thought about, but in an embedded way, relating to the present and to the past, for example in talking about families and friends who were unwell or who had died, and stories about the War. Doreen used her parents as an exemplar; she wanted to die like them. For Florence the template was similar; she looked to her mother's death to think about dying but this did not seem to bring the comfort that it did to Doreen, perhaps because her mother had died a traumatic, slow death. For most people it was not death itself that was as difficult as the nature of the future and dying. Florence stated:

You ought to be able to go when you want to, not when God wants you. I mean I'm 87; I'll be 88 in December. What future is there, honestly?

Her son suggested she should take control, for the future was what you made it. Florence replied *'What can I make of it when I can't see?'* Florence fell outside a medical

categorisation of “recognised dying” often operationalised clinically through the question, “would I be surprised if this patient died within the next year?” (Delamonte, Knapton, & Richardson, 2010). However she was voicing something about her feeling as though a part of her had already died; she seemed unable to live well in her increasingly dependent and out-of-focus world.

Many people talked about being present at the deaths of family members. A number of participants had been involved in bodily preparation after death. Jim had attended to his mother-in-law’s body and witnessed his wife’s sudden terminal event thirteen years ago. His discussion about death was pragmatic, though no less emotional for that. Prior to the first interview Jim had received a letter informing him of a friend’s death and connected this present event back to his wife’s death. Reflecting on the letter he narrated:

Yeah, she died [in 1984]. It was strange, we was watching the tennis, McEnroe, and ... she said ‘Oh Jim, I do feel funny,’ and she collapsed on the table. She had a cerebral, what do you call it? - cerebral accident or something it’s called. All the blood burst in her head, and she was in the hospital, she was only in there for about 8 hours and she died. And he (the Doctor) said, ‘If she recovered, she’d have been left a cabbage.’ So I said ‘I wouldn’t have minded that, I’d have looked after her.’ So in a way, it’s thankful she didn’t suffer, she died peacefully.

Through this recounting Jim seemed to be communicating something of his own questions about the process of how he might die. He returned to dying in his second (and last) interview and talked of looking over his shoulder, aware that death was there but not sure how it would be. He finished this interview abruptly, noting that of his nine siblings, only two were left:

They all died – all the lot. We're the only ones left. Three of us and I'm the oldest. I'm the governor now. Not sure for how long. I wonder... it's hard, I think I would like to stop [the interview] there...

Jim seemed to be reflecting upon whether, like his wife, death would come quickly, or would be more chronic and slow. However, talking about his own finitude appeared difficult to do.

There is a growing literature on the importance of individuals talking and planning for the future and dying in old age, most often with the support of professional carers (Seymour, Gott, Bellamy, Ahmedzai, & Clark, 2004). However, this study reveals a non-professional, hesitant language and discourse used by frail older people on connecting to the future, outside of medical diagnosis, prognostication or treatment options. It is not therefore that professional discourses are unimportant, but that they seem to marginalize conversations around dying and death from everyday life (Kellehear, 2005; Segal, 2000).

Within this study all participants spoke about dying and a limited future, yet this was embedded in their work of keeping going in their everyday lives, rather than a focused discussion around (for example) advanced directives and end-of-life preferences. The uncertain and dwindling progress toward death captured through this study could be said to be at odds with popular and professional ideas of a ‘good death’ in which awareness of dying and control are central (Seymour, Witherspoon, Gott, Ross, & Payne, 2005). Dying with frailty is a gradual and unpredictable process, involving accumulated vulnerabilities. McCue (1995) argues that developing into dying in old age is a ‘normal’ life course process. However, support for the natural development into death is undermined by the medicalisation of dying, which both pushes the phenomenon of death away and curtails support to those dying outside of medically defined prognostic categories.

Discussion

The study findings argue that frailty is a persistent liminal state. Participants’ narratives capture the feelings of uncertainty and loss experienced with progressive physical and psychosocial changes and an increased awareness of finitude. Moreover older people’s stories revealed considerable capacity to create daily routinised practices to anchor themselves and sustain connections within their imbalance. However the study also reveals the problematic nature of finding shared meanings between older people and health and social care professionals within the continual and shifting state of frailty.

The uncertain work of maintaining identity through frailty is held within a Western cultural response to ageing which is ‘bi-polar’ (Cole, 1992); a vacillation between

agelessness (the Third Age) and abject bodily decline into death (the Fourth Age). Frailty is often conceptualised as the transition point across which an older person passes from the Third to the Fourth Age. Belonging to the Fourth Age is a social identity conferred on people who are no longer “getting by or not able to manage their daily round” (Gilleard & Higgs, p122). This transition in social identities from the Third to Fourth Age is commonly seen as irreversible.

However, the frail elders in this study seemed simultaneously to be living across the Third and Fourth Ages. We suggest this persistently fluid state of frailty links with Turner’s (1974) concept of ‘marginal groups’. This is the name Turner gives to a separated group which displays the characteristics of a liminal group, in that members of the group are outside normal societal identities. Rather than clearly transitioning from one discrete cultural state to another, marginals inhabit both states at the same time. Marginals then are those who “are simultaneously members of two or more groups whose social definitions and cultural norms are distinct from and even opposed to one another” (1974 P233). These individuals experience a state of constant ambiguity where there is no resolution or transition from one state to another. This is the marginal or persistent liminal state of frailty where elders are continually redefining their identities.

Our interpretations argue that frail elders manage the ambiguities of this persistent liminal space by constructing their own personal habitual routines or personal scripts. Maintaining these personal scripts through frailty is important, yet can also bring difficulty. The risk of structured and habitual patterns breaking down was ever present

within the uncertainty of changing physical and social capacity and receiving “care”. Also rigid adherence to practiced ways of keeping going may prevent adaptation to the accumulated losses of frailty and the realities of physical decline. Paradoxically, the inability to accept assistance may lead to increasing helplessness and dependence rather than a more adaptive interdependency (Davenhill, 2007).

Integral to this study is the understanding that frail older people balance both loss and capacity in their everyday experience; holding together loss and creativity is important. However, current theoretical understandings and services for the frail old engage with the physical frail body rather than with the person in the context of their identity and their relationships. The study highlights the individual meanings within frailty and evidences creativity and development as well as physical decline. The experience of persistent liminality within frailty, we argue, requires an external and social engagement with the loss and capacity of older frail people. The study has set out a case to reverse the ordering of frailty, to return the focus to the person and their work of continually constructing identity and their relationships, through which the experience of the functionally frail body is mediated.

Study limitations

Whilst understanding that psychosocial theories are diverse and complex, this study aimed nonetheless to hold the tension between how both social and psychological entities mediate experience. Psychosocial interpretations of data may however be seen as placing interpretation on people and privileging micro processes over larger cultural structures

which shape experience such as class and gender. Further, recruiting through an intermediate care team meant that all participants had had some contact with formal services, which may not be the case for all frail older home-dwellers. Whilst not claiming to have found ‘the answer’, we believe that a combination of in-depth analysis of rich, detailed data, reflexivity and validation using theory, and different reflecting groups with diverse theoretical perspectives has allowed for a valid interpretation of the data.

Conclusion

This study argues that frailty in later life is a state of imbalance in which people experience loss of both physical and psychosocial connections. Yet frail elders work actively to retain anchorage in this state of imbalance through developing and sustaining connections to their physical environment, routines and social networks. Crucially, the struggle for frail older people to retain the balance between loss and continuity is held within the wider context of the gradation into death. However, holding together living and dying is challenging. It contests dominant cultural, welfare practices and policy frameworks that operate in binary modes: social or health; independent or dependent; living or dying, Third or Fourth Age. A less polarised response to understanding frailty in older adults is the recognition both of capacity and loss within a persistent liminal space. This conceptualisation argues for a rebalance away from polarized, discrete states towards an accepted transitional and uncertain cultural place where frail elders’ capacity and loss can be both acknowledged and supported over time.

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