The experience of living at home with frailty in old age: A psychosocial qualitative study

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ABSTRACT

Background: With enhanced longevity, many people in late old age find themselves frail and living at home, often alone. Whilst conceptualisations vary, frailty is often used in clinical practice as a directional term, to refer to older people at particular risk of adverse health outcomes and to organise care. Investigation of the experience of being frail is a complementary and necessary addition to international research endeavours clearly to define, predict and measure frailty. Currently, there is little empirical work exploring how people over time manage being frail.

Objective: The study aimed to understand the experience over time of home-dwelling older people deemed frail, in order to enhance the evidence base for person-centred approaches to frail elder care.

Design: The study design combined psychosocial narrative approaches and psycho-dynamically informed observation. Data on the experience of 15 frail older people were collected by visiting them up to four times over 17 months. These data were analyzed using psychosocial analytical methods that combined case based in-depth staged analysis of narratives with psycho-dynamically informed interpretations of observational data.

Setting: The study was carried out in the homes of the participants; all lived in a socio-economically diverse area of inner London.

Participants: 15 participants were purposively selected for living at home, being aged 85 or older and regarded as frail by a clinical multi-disciplinary intermediate care team.

Results: The findings challenge the negative terms in which frailty in older age is viewed in the predominant models. Rather, frailty is understood in terms of potential capacity – a state of imbalance in which people experience accumulated losses whilst working to sustain and perhaps create new connections.

Conclusion: This study suggests that holding together loss and creativity is the ordinary, but nonetheless remarkable, experience of frail older people. For frail older people, the presence of others to engage with their stories, to recognise and value the daily rituals that anchor their experience and to facilitate creative connections is vital if they are to retain capacity and quality of life whilst being frail.

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What is already known about topic?

- ‘Frailty’ in the literature is often used to describe the state of living in older age with accompanying vulnerability to functional decline.
• Internationally, researchers are focusing on clinical diagnosis, and ways to predict and modulate frailty.
• Little is known about the subjective experience of frailty.

What this paper adds

• A revised models of frailty in older age which is not always negative, thus challenging predominant models.
• A new conceptualisation of frailty which is dynamic and active where some connections (physical/social/emotional) are lost, others sustained and new ones created.
• A relationship centred approach to care is critical to ensuring older people living with frailty realise their goals beyond functional capacity.

1. Background

Global demographic trends report increasing longevity with a resultant rapidly ageing population (United Nations, 2007). The number of people living in the UK alone, aged over 85, is expected to quadruple to four million by 2051 with the majority continuing to live in a domiciliary setting (Office for National Statistics, 2007). Although some older people will continue to experience good health into late old age, many will live with decreasing functional capacity, increasing acuity and dependency on health and social care agencies. Frailty is the term increasingly used to describe the condition of people vulnerable to adverse health outcomes in later life. However, there is presently no single agreed frailty conceptualisation and resulting operational definition (Abellan Van Kan et al., 2008).

Conceptualisations of frailty have been categorised as either a “narrow” approach, focusing on purely medical/physical frailty, or a “broader” approach that takes into account psychological and social frailty (Van Campen, 2011, p. 15). Whilst these approaches are not mutually exclusive, the conceptualisation and operational definition of frailty within a “narrow” physical/medical domain has received proportionally more attention in the literature. The most commonly applied definition of frailty is as an age-associated biological syndrome characterised by a decrease in biological reserve and resistance to stress due to a decline in several physiological systems. The main consequence is an increased risk for multiple adverse health-related outcomes (Campbell and Buchner, 1997; Walston et al., 2006). However there is a continuum of opinions of the essential characteristic, causes and clinical consequences of being frail. Fried et al. (2001) identify criteria to determine a frailty phenotype (three or more of weight loss, muscle weakness, and slow gait speed, low levels of physical activity and self-reported exhaustion). Whilst widely cited, the predictive value of these physical functioning domains for adverse outcomes remains unclear (Avila-Funes et al., 2008) and other criteria, e.g. cognitive decline (Abellan van Kan et al., 2010) and mental health and accumulated vulnerability (Bergman et al., 2007) have subsequently been identified as important in determining adverse health related outcomes. Bergman et al. (2007) argue that frailty can provide a conceptual basis to move away from an organ or disease based approach towards one that also incorporates psychological and social aspects. The integral or broader definition allows for the inclusion within frailty conceptualisation of social functioning (Nourhashemi et al., 2001; Schuurmans et al., 2004), social relationships (Tilburg et al., 2004) and psychological frailty, e.g. self-reported anxiety and loneliness (Comijs, 2011; Markle Reid and Browne, 2003).

However, there is currently no consensus on the concept nor an operational definition of frailty. Van Campen (2011, p. 15) notes that the term “frailty” has been used in clinical practice primarily as a heuristic or directional term to refer to risk groups and to organise care rather than as a diagnostic tool. Examples would include clinical pathways for frail elders which use a constellation of criteria based on emergency admission to hospital (Allen et al., 2005) and WHO (2004, p. 22) glossary of terms for community health and social services for older people that defines a frail older person as “an older person in need of a substantial level of care and support”. These clinically driven working definitions add another lens to the complexity of conceptualising frailty. However, there has been little research to gather the experience of those deemed frail. The small body of existing literature on the subjective experience of “being frail” argues that the label is often actively resisted by older people themselves, who distinguish the body one is (self-identity) from the body one has – a physically vulnerable object (Becker, 1994; Kaufman, 1994). This study used a case based narrative approach to gather stories from community dwelling elders deemed frail by a clinical multi-disciplinary intermediate care team. The intention was to explore how these older people spoke about and experienced their everyday lives over time. Capturing the temporal nature of experience is important in order to understand the meanings and subjectivities of older frail people and to design appropriate person centred care for this group.

2. Methods

2.1. Aim and design

The study aimed to understand the experience of home-dwelling older people with changing states of frailty. The purpose was to enhance the evidence base around person-centred nursing care for this group. Using a broad concept of frailty encompassing social, psychological and physical domains, the research design was 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; Rosenbeil, 2006). Thus data collection and analysis takes account of emotions felt as well as words spoken.

2.2. 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 multidisciplinary teams work across domiciliary and
community facilities to provide intensive support at times of particular vulnerability and to prevent or minimise hospitalisation. Participants were purposively selected for living at home and being regarded as frail by the intermediate care team. Frail community dwelling elders were defined by the team as people of advancing age, unable to carry out independent activities of daily living (Lawton and Brody, 1969) and considered to be vulnerable to physical decline. People with a diagnosis of dementia were excluded from the study although the study design and ethical procedures took account of cognitive deterioration over time. Two people declined to be in the study, one because English was a second language and another who withdrew because of rapidly deteriorating health.

The study gained ethical approval from Ealing and West London Mental Health Trust. A staged process of involvement was designed where first contact was through the intermediate care team, followed by explanatory material devised and piloted with older people and then an introductory researcher visit. Ethical clearance was gained for both taped and written consent (Baldock and Hadlow, 2002) as signatures can be threatening for some older people (Chouliara et al., 2004). The study used a processual consent design (Dewing, 2002) which was contextual. Hence at each cycle of data collection written or verbal consent was gained and situational and relational cues, attended to before and throughout the interviews.

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). 15 people (5 men and 10 women, aged 86–102) were included in the study. The majority were widowed and lived alone. All had some contact with welfare services, although this ranged from intermittent contact to daily involvement. Table 1 details the demographic characteristics of the participants. Two participants chose to be interviewed with their spouses and whose narratives were jointly told. Within analysis these dyadically constructed accounts were considered as singular cases.

### 2.3. Data collection

Two psychosocial narrative approaches; the Biographic Narrative Interpretative Method (BNIM) (Wengraf, 2001; Wengraf and Chamberlayne, 2006) and Free Association Narrative Interview Method (FAINM) (Hollway and Jefferson, 2000), were used to elicit narratives of living with 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 case-based analysis.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age (at end of data collection)</th>
<th>Marital status</th>
<th>Living arrangements</th>
</tr>
</thead>
</table>
| 1 Doreen (M)    | 87                              | Widowed        | Own house lives by herself
|                 |                                 |                | Twice weekly private carer/family twice weekly |
| 2 Alfred (M) and Elsie (F) | A = 88                        | Married        | Own house live with unmarried son (twice daily social care) |
|                 | E = 87                           |                | Health care as needed |
| 3 Jim (M)       | 92                              | Widowed        | Sheltered housing |
|                 |                                 |                | Cousin Ida in same block |
| 4 Lillian (F)   | 91                              | Widowed        | Own house lives by herself |
|                 |                                 |                | Social carer daily/rota of friends |
| 5 Monica (F)    | 86                              | Separated      | Rented house lives on her own |
|                 |                                 |                | Twice weekly visits by family |
| 6 Joan (F)      | 87                              | Widowed        | Own house lives by herself |
|                 |                                 |                | Daily social services |
| 7 Jack (M)      | 86                              | Widowed        | Council flat lives by himself |
|                 |                                 |                | Intermittent health care contact |
| 8 Hetty (F)     | 87                              | Widowed        | Not wanting social service support |
|                 |                                 |                | Own house lives by herself |
| 9 Florence (F)  | 87                              | Widowed        | Twice weekly physio |
|                 |                                 |                | Network of friend and family |
| 10 Flora (F)    | 95                              | Widowed        | Own house lives with unmarried son |
|                 |                                 |                | Daily social care |
| 11 Eli (M)      | 102                             | Widowed        | Own house with 24 h private care |
|                 |                                 |                | Health care weekly |
| 12 Bob (M) and Penny (F) | B = 86                  | Married        | Own house |
|                 | P = 87                           |                | Social carers coming in daily |
|                 |                                 |                | Health care intermittently |
| 13 Esther (F)   | 96                              | Widowed        | Own house lives with unmarried daughter daily social care |
| 14 Pat (F)      | 98                              | Widowed        | Own house lives by herself |
|                 |                                 |                | Social care and health care three times a day |
| 15 Evelyn (F)   | 87                              | Widowed        | Own house lives by herself |
|                 |                                 |                | Social care three times a day |

Narratives are collected through a two-staged face-to-face process. In stage one the interviewer (in this study CN) offers a single opening question to support rather than direct the content and telling of a story. Once the question is spoken the researcher listens but does not interrupt. Phase 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 were taped, transcribed verbatim and subject to a staged analytical process.

BNIM was the method of choice, but for some interviews adherence was difficult. Primarily due to their frailty, participants became cognitively tired and needed prompts to recall their thoughts. In this case the more participative, conversational approach of FAINM was used. Field notes were informed by psycho-dynamic observation techniques (Bick, 1964). This is a method of reflecting on the participants’ and researchers’ emotions and their possible meanings communicated within the interview (Nicholson, 2009).

BNIM uses selected gold cases (subject to greater depth of data collection and analysis), which are then compared and contrasted against secondary cases. Three gold cases (two individuals and one couple) were subject to four rounds of interviews. The ‘gold cases’ were chosen after the first round of data collection and selected for demographic and methodological variance that arose in eliciting and listening to stories of frailty and for variance in self-reported vulnerability to adverse health-related outcomes. Of the remaining secondary cases, 10 took part in 2 interviews over 6 months and 2 participants declined to be re-interviewed. Table 2 summarises data collected, with the 3 ‘gold cases’ highlighted in bold; pseudonyms are used for all participants.

2.4. Data analysis

A modified BNIM analysis was used which combined the case-based staged interpretative process of BNIM with data collected through psychodynamic observation. The BNIM analytical process has some similarities with grounded theory in using analytical steps of extraction, hypothesis generation and testing data. However, detailed case-based analysis of selected gold cases using biographical data, text sequilisation, salient stories and field notes aimed to retain the connection between the lived life and the told story for as long as possible. Thus rich and detailed analysis, emphasising the discordant and divergent themes within each case is used to build up a thick description of the particular and generate themes through which the remaining 12 secondary case narratives were read.

The three gold cases were subject to cross case analysis using an iterative and recursive process of syncretic perception (Froggett, 2007; Froggett and Holloway, 2010), similar to Borkan’s (1999) immersion/crystallisation method of qualitative data analysis. The main researcher (CN), cyclically alternated periods of intense engagement with the data with periods of researcher reflection and only then were generalised themes taken to the secondary cases for further analysis and cross checking.

The researcher’s (CN’s) analysis and interpretations were validated by a psychodynamic observation group involving psycho-dynamically trained practitioners, one-to-one supervision and a reflecting panel at the point of cross-case analysis. The reflecting panel intentionally brought together 3 academics from social science, gerontology and anthropological backgrounds and 3 clinicians from nursing, social work and occupational therapy to test the analysis and strengthen or weaken interpretations of emergent themes.

3. Findings

The findings question the prevailing concept of frailty as incapacity. Rather, frailty is understood as a state of imbalance in which people experience the loss of some connections whilst working to sustain others and to create new ones. However frailty was not a word people used to define themselves or their experience of everyday living. Rather old “frail” people demonstrated capacity to overcome or find others to overcome their physical, emotional

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Interview 1 (6 months later)</th>
<th>Interview 2 (6 months later)</th>
<th>Interview 3 gold cases (6 months later)</th>
<th>Closing interview gold cases (6 weeks later)</th>
<th>Total contact time with participant (h)</th>
<th>Psychedynamic field notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Doreen</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>4 h and 33 min</td>
<td>X</td>
</tr>
<tr>
<td>2 Alfred and Elsie</td>
<td>Xx</td>
<td>xx</td>
<td>xx</td>
<td>Xx</td>
<td>5 h and 48 min</td>
<td>X</td>
</tr>
<tr>
<td>3 Jim</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>2 h and 3 min</td>
<td>X</td>
</tr>
<tr>
<td>4 Lillian</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>3 h and 14 min</td>
<td>X</td>
</tr>
<tr>
<td>5 Monica</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>2 h</td>
<td>X</td>
</tr>
<tr>
<td>6 Joan</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>5 h and 35 min</td>
<td>X</td>
</tr>
<tr>
<td>7 Jack</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>1 h and 52 min</td>
<td>X</td>
</tr>
<tr>
<td>8 Hetty</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>2 h and 43 min</td>
<td>X</td>
</tr>
<tr>
<td>9 Florence</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>2 h and 51 min</td>
<td>X</td>
</tr>
<tr>
<td>10 Flora</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>3 h and 14 min</td>
<td>X</td>
</tr>
<tr>
<td>11 Eli</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>6 h and 18 min</td>
<td>X</td>
</tr>
<tr>
<td>12 Bob and Penny</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>1 h and 19 min</td>
<td>X</td>
</tr>
<tr>
<td>13 Esther</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>2 h and 8 min</td>
<td>X</td>
</tr>
<tr>
<td>14 Pat</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>2 h and 47 min</td>
<td>X</td>
</tr>
<tr>
<td>15 Evelyn</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>1 h and 10 min</td>
<td>X</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>13</td>
<td>3</td>
<td>3</td>
<td>53 h and 55 min</td>
<td>15</td>
</tr>
</tbody>
</table>
or social vulnerabilities. However, participants did all speak of loss over time, loss of physical capacity, social status, friends and family. For most this opened up discussions around dependency, finitude and their experiences of societal and welfare systems that often militated against the work of managing being and feeling frail.

Three main themes arose from the analysis: Losses and disconnects within frailty details the experience of physical, social, and psychological loss; Sustaining connections presents the strategies that frail older people actively employed to create anchorage and Creating connections addresses the potential that older people found within the imbalance of frailty to find new ways of connecting to themselves and to the world around them. These 3 themes were distinct but not sequential. Rather the work of holding together loss and capacity through losing, sustaining and creating connections was overlapping and multifaceted.

3.1. Losses and disconnects within frailty

The losses associated with physical decline were a central theme across all the interviews although communicated in different ways. Some participants were very explicit about being able to do less, whereas others communicated this loss more implicitly. For example Jim used to do all his own housework, Monica wished she could keep the house clean. The loss of physical capacity was painfully recounted in Alfred and Elsie’s narrative and in CN’s observational field notes. He started by wondering whether he had a story (or a life) to tell anymore, then noted,

I suppose if you was like that from birth you perhaps wouldn’t notice it so much but when you in, say, 70 years, 60 years you’ve been normal, to get like that it’s… well, not heartbreaking, but it is really. And I can’t… what’s the word? Change it, you might as well be out of it all together… (A&E 2.3)

Following the interview CN recorded these observational data,

I feel that sense of, yeah, what is going to happen to you, (long pause) and I want to, and I wanted to say, to keep saying it’s OK, it will be OK and a powerlessness that I cannot do that (long pause)… and I feel grateful to be out of there.’ (Field notes, case 2, 29 November 2006)

The psycho-social interpretation of these data was that CN had taken on and was feeling some of the loss of Alfred. She was herself unbalanced, and in some respect, filled up with frailty. Whilst not all participants spoke so strongly about the loss of physical mobility, or evoked a strong emotional response, the loss of physical function evoked a loss of certainty about how the world was.

Some participants expressed a sense of shame at being seen with a walking aid, or wheelchair. Indeed, some preferred not to venture outside. For Lillian, it was the unwelcome attention that this would draw that she disliked. Her desire to go out only if she was walking independently meant she did not go out at all. Such recourse to independence and laudable resistance may over time be to Lillian’s detriment. The uncertainty of being imbalanced seemed to precipitate unease. Participants were unsure of when it was legitimate to ask for help; access to society was often denied through poor facilities and being at home seemed paradoxically to increase social disconnection. Jim summarised his experience thus,

'It’s about getting through the day, just holding it together, as best you can, you fall down, you pick yourself up, you keep going as best you can, till you, and well you can’t keep it up for ever. (jmz2/14)

The participants narrated a loss of autonomy and a challenge to self-identity that was often evoked through contact with external domiciliary services. Participants were unsure of when carers would come and for some, what they would do when they were there. Pat revealed the difficulty of establishing routines when you are reliant on someone outside to help you:

'I’m usually half up anyway when they come. Not with the Polish girl, I’m not then, she comes early, 7.30 but you never know when the one from Jamaica, she turns up at all hours and then not at all’. (P1/6)

The unpredictable nature of allowing outsiders in was too difficult for some; Eli and his family chose to manage without outside help and Alfred and Elsie stopped the carers within 6 months of the study. For others they recounted being shouted out, feeling invisible, talked about and talked over. Such occasions created a loss of confidence and personhood, we are just old that’s why they do not care (Pt 2/3) was a recurring theme.

In all the narratives there was reference to the challenges and changes to social identity and positions in the world due to frailty. Joan’s reflection that ‘it’s a different pace of life now’ indicated more than a change in stride. Participants narrated how they were perceived differently by friends and by family following a period of physical vulnerability. The change in perception was often recounted as a concern as to whether informants could still cope at home. Hetty’s son wanted her to move and at least get a security alarm although she had ‘not got round to getting one. Hetty’s response was one of resistance, though in our subsequent meeting 6 months later she noted that any bump or bruise, e.g. when she fell asleep at the table, revived the issue. ‘He is now saying get a button or move into a retirement home, what choice is that?’ (H2/1.)

The narratives suggest that the balance between autonomy and dependence and changing roles is complex. Although the experience of families and carers was not deliberately sought in this study, the narratives of frail participants revealed the difficulties of changing states for relatives and friends and the varied responses that this evoked. This may be of particular relevance to those living in late old age whose children are themselves entering the third age. The interpretations suggest that family as well as the older person find themselves in a place of transition during a parent or spouse’s frailty. Thus the complexity of loss of place for the ‘frail’ older person is underpinned by
the difficulty of re-establishing stability within a family when other people are similarly imbalanced.

3.2. Sustaining connections

Participants responded to the imbalance and losses of frailty by employing strategies that reconnected them to their bodies and created anchorage in their daily lives. Within all accounts there was a greater consciousness of the body and the need to balance changing bodily capacity within habituated daily routines, ‘Taking a break’, ‘pacing oneself’ and ‘being careful not to overdo it’ were common expressions across the stories. The intention of participants to keep physically active was set against the common experiences of pain, increasing tiredness and lack of strength. Within the accounts there were long descriptions of how the body was looked after, often grounded in the daily tasks of eating. What participants ate, how to co-opt others when unable to prepare or cook food yourself and how to make the best of pre-cooked meals were all discussed.

The work of increasing bodily capacity through exercise and adaptations was evident in many cases. Exercises for some were welcomed. Joan saw them as both helpful in sustaining movement but also in filling her day, ‘I still have to do certain exercises to improve my leg muscles so I don’t have a huge amount of time on my hands’. She welcomes the aids from the physiotherapist and details how she adapts to wearing slippers and walking with a stick. However, for others exercises and adaptations were seen in a more ambiguous light. Doreen noted that her exercises did not help and that learning something new or meeting new people was difficult at her time of life.

For most respondents, much of their effort lay in maintaining and sustaining their place in their immediate world. Daily routine was an important anchorage, grounding people in the present and in a wider continuity of social relations. Rhythms of the day were important, often built around mealtimes, a particular television programme or a daily telephone call to a friend or neighbour. People talked of holding off from a pleasurable activity until later in the day; Esther restricts her cup of tea until the afternoon, Jack his newspaper until after he’s had supper. Doreen’s narrative details the vigilance of daily routine, seemed to betray a greater fear of what might happen should she stop her daily rituals. Her story detailed the exact timings of her routine and goes on to talk about a friend, now dead. She linked the stopping of routine as the point which tipped her friend into dying.

‘I can rest very well in bed but when it gets to 5.45 I think, oh, yes, I’d love to stay like this but I know I mustn’t -. 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 I sort of think to myself no, you mustn’t do it, you’ve really’ (D2/6)

The rituals of sustaining rhythm enable anchorage to wider social and cultural norms within the unsteady state of frailty. However, the risk of breaking these ritualised patterns is ever present within the uncertainty of changing physical and social capacity. Indeed, allowing in services often disrupted these patterns. People struggled to accommodate carers who arrived to put them to bed too late or too early, or failed to appreciate the significance of the timings of the day.

3.3. Creating connections

The findings reveal the potential as well as the difficulty within the unbalance of frailty. Some participants were able to relate to their bodies and surroundings in new and creative ways. Doreen talked of rigging up a set of pulleys and string so she could hang out her washed sheets and Joan used the handheld claw to hook her cup on and holding the frame with her other hand hopped into the kitchen. Within the study there were a number of examples of how people responded creatively to the reduced space that they inhabited. Pat created an indoor garden, Doreen repositioned her home around the chair in which she sits all day and Flora co-opted into her space the street light outside her house.

For some, new connections were created by allowing a level of inter-dependency on others. This ability to create connections through inter-dependency was vividly described in Flora’s narrative of continuing to be creative in the garden. Although no longer able to garden herself, she taught her carers how to sow and plant out seeds. It appears that although physically almost totally dependent, she retained enormous capacity to do things differently and thus to develop new connections. In the following extract she explained how she fell in the garden and her response.

‘Well, that’s difficult for me so I’m now training a whole lot of junior gardeners. You’ll be surprised, I’m training Jackie and anybody that comes now who’s not a gardener; I’m training a whole new generation, because you see I have to remember every day.’ (Fl2/1)

Participants recognised the importance of carers coming in as a way of being kept an eye on and having someone to talk to. That is not to say that the activities themselves were not necessary, but in recounting everyday experiences it was the interpersonal contact, which was most often discussed. This was particularly the case for people who lived on their own. Pat had recently had cataracts removed and nurses visited twice daily to administer eye drops. She explained their routine and concluded

‘But it’s nice seeing all these people, it keeps… helps me with companionship living on my own. Oh I see my son and daughter, they come when they can but they. . . . one lives in xxx (the North) and the other lives in xxx (the Home Counties)’. (P2/2)

Within this study many participants used frailty as a place in which to create connection, to themselves and others, indeed this study and their involvement in it, could be seen as such an exemplar.

4. Discussion

This study argues that in living with frailty over time, older people demonstrate creativity even as they experience
loss. This creativity however is not the figurative creativity of art or music, which is often espoused as a way of engaging and remarking on the abilities of frail older people. Rather it is a relational creativity underpinned by the capacity to connect to their changing circumstances and adapt within the ambiguity and disconnections of being frail.

An inherent part of older frail people’s capacity was evidenced through the work of creating everyday routines. These, it is argued, provided anchorage and stability within the vulnerabilities of being frail. Baldox (1999, p. 95) suggests that older people have to “choose and construct their own routes through unscripted old age.” There are few, if any, shared cultural understandings to provide a course for frail elders (Holstein and Waymark, 2005). The findings suggest that frail older people respond to this socially unscripted old age by creating personalised rituals.

Philpin (2002) notes the term ritual is often used in a pejorative sense and linked to unthinking and routinised action. However, what is missed in such critiques is the latent meaning of the ritual and the symbolism that is stored within it. Turner (1982, 1995), an anthropologist, suggests that rituals are storehouses of meaning, e.g. representative of cultural and individual meaning, which hold people in times of ambiguity. For example, Eli’s ritual activity of making breakfast is maintained despite his rapidly declining physical capacity. This both feeds him and sustains a sense of control. As time goes on, his daily omelette making is supervised, becomes a shared task with his daughters and ultimately is given to others to perform. He maintains this routine until a month before his death.

However, the findings suggest that experiencing frailty requires a delicate balance successfully to integrate previous, present and future realities. For some the personal rituals established though daily routine seemed to prevent them from engaging with their present losses. Within psychodynamic theory, adaptation to loss is an important part of development. Loss is not necessarily related to an actual death, but to the sense of separation and letting go experienced throughout the normal transitions of life. The integration of loss through mourning is a social as well as an individual task. However social connections are often missing for frail older people. Either because their losses are unseen (Thompson, 2002) or point towards an unwelcome future avoided by others (Dartington, 2010) or because social frailty diminishes connections with others.

The multi factorial nature and complexity of being frail is illustrated in this study. The experience of balancing loss over time with considerable capacity to work and adapt within frailty effects the goals older people may have and their understanding of living well with frailty. This dynamic between physical social and psychological factors is recognised in recent integral conceptualisations of frailty (Gobbens et al., 2010). However explicit recognition of the importance of the interplay of bio-psycho-social factors in frailty is also required in policy and practice. Models of working with loss, e.g. Blanchard et al’s. (2009) re-integrative model for old age psychiatry and end-of-life care frameworks for example, Knight and Emanuel (2007) are clinical exemplars. These models emphasise reintegration of loss and the investment of energy and care into creative adaption rather than cure. Such approaches are important to rebalance the present predominately negative conceptualisations of frailty and refocus on the creative capacity and potential to age well whilst being frail.

5. Strengths and weaknesses

The study was exploratory and findings do not confer generalisability due to small sample size. However qualitative research is concerned with information richness and on exploring ideas from data rather than establishing prevalence, indeed the subjectivity of being frail is important as it allows for a focus on individuals own perspectives (Richardson et al., 2011).

Within this study, attention to the trustworthiness of qualitative findings was through assimilating theory and the practice of psychodynamic approaches, clinical supervision and the use of reflecting teams to strengthen interpretive hypotheses and lessen others. Attempts at confirmability included researcher reflexivity (Cutcliffe, 2003) which attended to the position and influence of the main researcher in both data collection and analysis. Within psycho-social research this moves beyond the researcher’s social positioning to the emotional response and its influence on shaping interpretation (Clarke, 2006; Hollway, 2006). The psychodynamic observation method provided a systematic, wider group process within which to address reflexivity. Psychosocial interpretations of data can be seen to some as placing interpretation on people and privileging micro processes over the larger cultural structures such as class and gender, which shape experience. Whilst understanding that psychosocial theories are diverse and complex, nonetheless this study aimed to hold the tension between how both social and psychological entities mediate experience. Whilst not claiming to have found “the answer” a combination of in-depth analysis of rich and detailed data, and the reflexivity and validation using theory and reflecting different groups with diverse theoretical perspectives has allowed for a valid interpretation of the data.

Frailty, in this study was determined locally by clinicians working with older people. Whilst this operational definition of frailty is not identified in the literature, it is clinically driven and allows for a wider multi factorial and enacted construct of frailty to emerge.

The research initially aimed to look at how experiences of frailty may change over time but 17 months was an insufficient period over which to capture large changes for most participants. Whilst leaving a gap of 6 months between interviews led to two participants leaving the study it did illuminate both changes and stability within the everyday experience of frailty. E.g. 9 participants reported unplanned hospital admissions over the period of data collection and narratives explored the challenges of changing states within physical, social and psychological frailty.

6. Conclusion

This study sought to illuminate the subjective experience of being a frail older person. It argues that frail older
people retain enormous capacity to work with the challenges of accumulated loss in physical, social and psychological domains. However, the extraordinary work of relating to their ordinary world in a different way rarely equates to the predominant stereotypical image of frail older adults which focus on vulnerability. Van Campen (2011, p. 187) eloquently argues that frailty conceptualizations must aim to maintain quality of life, not just to eliminate specific disease or complaint. These findings concur and argue for a more deliberate focus on the work of holding together loss and capacity as part of a person centred approach to care for frail older people.

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References


