

Holding it together: A Psycho-social exploration of Living with frailty in old age.

Abstract

Background

With enhanced longevity, many people in late old age find themselves living at home, often alone, with increasing frailty – a slow dwindling pathway of decline towards death. However there is no empirical work exploring how people over time manage this experience. Whilst current policy drivers focus on ‘care at home’, there is a real distinct lack of understanding of what this means for older people themselves. With increasing life expectancy the care of older people is a pressing and growing issue of welfare, politics and personal concern. The implications from this study are absolutely key to developing better health and social care services.

Aim

The aim of this study was to explore how people over 85, living at home experience frailty and the impact of changing circumstance on their perceived physical, psychological and social worlds.

Methodology and Methods

The complex dimensions of social, psychological and physical frailty require a research methodology that moves beyond purely social research. This study created a new method combining psychodynamic observation,¹ Biographical Narrative Interpretative Method² and use of a creative expressions pack. This innovative methodology supported the significance of people’s stories told in their own way, using different creative media. Crucially it recognised that life history frames experience and that meaning is expressed through emotions, as well as words.

Over the course of a year, 15 people were repeatedly interviewed, up to four times, in their own homes. The analysis and interpretation of these rich data was staged, building up three in-depth whole life cases which were compared and contrasted with each other. The emergent themes were further analysed against the stories of the

other twelve participants using an iterative and recursive process of syncretistic perception³. Through the process of cognitive and emotional immersion in the data, the diversity and commonality of experience emerged. The researcher's analysis and interpretation of the data was validated by the ongoing use of a psychodynamic observation group, psychodynamic supervision and a reflecting panel of experts at the point of cross case analysis.

Findings and Discussion

The findings question the prevailing concept of frailty as a period of inevitable decline. Rather, frailty is understood in terms of **capacity** - a state of unbalance in which people experience *the loss* of some connections whilst trying to *sustain* others and perhaps *create* new ones.

Loss of connections

Loss and its personal and collective sequel is a central experience of frailty and is inextricably linked to failing physical bodies. The interpretations suggest that the accumulated losses of bodily appearance, activity and independence lead to a greater loss of trust and place in the world. For some it brought both a sense that they were old and a tussle between their internal idea of themselves and the social, often ageist, experience of being around other people. For many this unbalance brought a mistrust, not only of their bodily capability but of the wider organisational bodies on whom they were more or less dependent.

Sustaining Connections

The findings note that people responded to the emotional unbalance of frailty by attempting to re-connect to their previously known worlds. Re-connecting to memories, past habits and relationships seemed to provide some participants with assurance and significance. For many respondents much of their effort lay in maintaining and sustaining the rhythms of daily life through managing and refining routine. Daily rituals helped to anchor participants in the present, give comfort and mourn the inherent losses of older age. However, the interpretations suggest that experiencing frailty requires a delicate balance successfully to integrate previous, present and future realities. For some the ritualisation of daily routine and recourse to

the past seemed to prevent them from engaging with their present position. For others dependency on welfare services meant daily rituals were interrupted or ignored.

Creating Connections

The findings reveal the potential as well as the difficulty within the unbalance of frailty. The interpretations suggest that many participants in this study had integrated and adapted within frailty, and thus bridged into a new way of connecting to themselves and to their worlds. Participants related to their bodies, their surroundings and other people in new, creative and differing ways; in particular, by connecting to and talking about their future through associations to past, present and future relationships. Although experiences were diverse, all participants seemed to hold “being frail” within a context of a limited future. This space between life and death is not held well within current policy and practice. Rather ‘dying work’ is held within a professional palliative care ideology and seen as something to be sequestered, not part of the normal development of the life course.

Conclusion

This study suggests that **holding together** loss and creativity is the ordinary, but none the less remarkable, experience of frail older people. Creativity within psycho-social interpretations of frailty is linked to the capacity to mourn. In frailty, it is necessary to mourn one’s own life before it is possible to invest part of yourself in people and things that will outlive you. For frail older people the presence of people to engage with stories, recognise and value the daily rituals that anchor experience and facilitate creative connections is vital to retain capacity, quality of life and the natural development into dying. However, the study suggests that this engagement is compromised by loneliness, ageism and the present overemphasis in health and social systems on purely physical functionality.

Contribution to Nursing Scholarship and healthcare policy and practice

This thesis is innovative in several ways: It

- questions previous understandings of frailty
- informed the forthcoming 'Best Practice for Older People in Acute Care Settings (BPOP): Guidance for Nurses'⁴ (distribution - 300,000 nurses)
- informed the National Council of Palliative Care publication on 'End of life care and older people with multiple conditions.'⁵
- identified a creative and structured technique that could be used by health professionals to draw out people's everyday stories and their emotional resonance, thus focusing on older people's **capacity** (currently being tested as part of post doctoral work).

(word count 999 excluding references)

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2 Wengraf, T. (2008) Life-histories, lived situations and ongoing personal experiencing. The biographic-narrative interpretive method: B.?.I.M. interviewing and interpretation 1st November 2008. version 8.11b [Unpublished guide]

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4 Bridges, J., Flatley, M., & Meyer, J. 2009, "Older people's and relatives' experiences in acute care settings: systematic review and synthesis of qualitative studies", *International Journal of Nursing Studies*, vol. [In press].

5 N.C.P.C. (2008) *Multiple Conditions: Multiple Challenges - Exploring Palliative and End of Life Care for Older People with Multiple Conditions*. London

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