

Research

Perceived factors which shape decision-making around the time of residential care admission in older adults: A qualitative study

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Aim: To understand the perceived factors that shape decision-making around the time of residential care admission in older people.

Method: Two qualitative methods (telephone interviews at intervals post discharge from geriatric inpatient care and face-to-face interviews with older people and their family carers) were used as part of a multiphase mixed methods study of a cohort of 144 older people discharged from medical wards in a subacute assessment, treatment and rehabilitation facility.

Results: Key topics and themes were derived from interviews: the role of the informal carer and other community supports, attitudes to decision-making and loneliness were key aspects of social context. Physical health, the experience of repeated hospital admissions and health professionals' attitudes to repeated admissions were also seen as important.

Conclusions: Social context as an essential component of older people's decisions to enter aged residential care is highlighted in this qualitative study.

Key words: frailty, residential care admission, social context.

Introduction

Frailty, an increasingly recognised problem in older people, has attracted much research in recent years. Research has tended to focus on physical attributes, such as the five features described by Linda Fried [1,2]. Others have argued that there is much more to frailty than this: it is a dynamic state reflecting interactions between the older person and

his or her environment. Barrett [3] called for research to 'examine the social construction of frail older people as a target population in social and health care sectors' and made 'a case for research to improve our understanding of the role of social support networks in mediating the frailty process'. Frailty is often seen as a lack of physiological reserve interacting with an older person's social assets and deficits [3]. From a physical perspective, the trajectory of decline in frailty seen in older people may be influenced by interventions such as exercise programs, which have been shown to improve outcomes [4–7]. However there is less research on the social context of frailty, and this study set out to explore this issue.

Many frail older people enter residential care when they are no longer able to manage living in their environment. Many factors contribute to the decision to enter residential care.

A recent New Zealand study [8] of residential care admission found that caregiver strain and time spent alone during the day predicted the likelihood of residential care admission.

In our previous work [9,10], we examined the predictors of outcome for frail older people after their discharge from specialist subacute geriatric care. Frailty was a key predictor of residential care admission along with dementia, further hospital admissions and self-rated health. However, the quantitative model only predicted about 40% of residential care admission and it is clear that other unmeasured factors contribute to admissions to residential care. In particular within the quantitative framework we found it difficult to measure aspects of social context and the influence of these on older people's decision-making.

Qualitative methodology is gaining increased recognition in the medical community as a way of broadening research topics, especially into social phenomena. Qualitative research enhances user involvement, and can highlight areas which would remain hidden within quantitative studies [11]. It allows study of topics within the complexity of 'real life' and can aid researchers to gain a more complete understanding or interpret quantitative data more fully [12].

In this paper we present a qualitative analysis of data from a cohort of frail older people discharged from specialist subacute geriatric medical care. The aim of the study was to describe in-depth factors related to subsequent institutional-

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sation and in particular to highlight the perceived role of social context in preventing or precipitating residential care admission.

Methods

We used two qualitative methods to broaden our understanding of the experiences of frail older people after their discharge from hospital and their decision-making about whether and when to enter residential care. The study began with a prospective cohort study conducted at a sub-acute geriatric unit, which provides medical care and multidisciplinary team rehabilitation for patients over the age of 65 years, 75% of whom have undergone an acute hospital admission. These patients are unable to be discharged directly from their acute hospitalisation due to loss of function associated with their illness. The other 25% have been admitted from home, typically with geriatric syndromes such as falls or confusion. The study took place on the general wards; specialist stroke rehabilitation, orthopaedic and psychogeriatric wards were excluded. Other exclusion criteria were age less than 65 years, non-English speaking, being discharged home for terminal care and severe dementia such that patients were unable to give consent. Informed consent was given by all participants and the study had the approval of the regional ethics committee.

Quantitative measures included function (using the Functional Independence Measure, FIM [13]), frailty (using the Edmonton Frail Scale, EFS [14]), cognition (using the modified mini-mental state examination, 3MS [15]) and comorbidities (using the Charlson Index, CI [16]). The EFS was chosen for its broad definition of frailty incorporating physical, mental and social factors. The results of this quantitative analysis are presented elsewhere [10].

Following discharge, participants were telephoned at 3 and 6 months. Three open-ended questions were asked: 'what is going well?' 'what is going badly?' and 'what would make a difference to you being able to remain at home?', or for those who had already moved into care, 'what could have helped you to remain at home?' Notes were taken during each

interview and broken down into key statements, with several statements noted from each interview. Statements were grouped in topics by the interviewer, and the number of times a topic was mentioned was recorded.

Key topics from these telephone interviews were then examined in more depth with a purposively selected group of 15 participants from the wider cohort. This group were all discharged in the same time period prior to the interviews, and involved 8 pairs, matching by age and sex those who had entered residential care with those who had remained in their own homes. (One person who entered residential care but then subsequently returned home was interviewed twice.) Participants were asked at the time of the interview to identify their main carer, and this person was also contacted and interviewed. This person was defined as 'the person providing the most physical, mental, emotional or practical support to the older person' as described by the older person themselves, and did not have to be resident with the older person.

Interviews were semi-structured. The key topics for each interview are shown in Table 1.

The interviewer used these topics as a guide, but was able to deviate in order to examine issues of importance in more depth as they arose. Interviews were audio-taped and transcribed by a professional transcriber. Analysis was carried out using a general inductive approach [17]. Interviews were read multiple times by the principal researcher and broken down into key themes. The research group then carried out thematic analysis, using comparative sorting and cross-checking with topics derived from the telephone interviews, leading to the interpretation of the themes reported in this paper.

Results

There were 273 discharges from our unit during the 6-month study period. Of these, 159 were recruited into the quantitative study as described previously [10]. Most of the 114 people not included in the study were not referred by their clinical teams and hence were never assessed. Of those assessed and then excluded, four had more than one admis-

Table 1: Key face-to-face interview topics

Rest home participants	Own home participants
Factors important in making the decision to move into rest home How could rest home admission have been prevented?	Factors important in enabling you to remain at home
How did support at home affect your decision? How did disability affect your decision? How did health problems affect your decision?	What factors would cause you to consider rest home care? How did support at home affect your decision? How did disability affect your decision? How did health problems affect your decision?
Rest home carers	Own home carers
Factors important in making the decision to move into rest home (specifically ask about cognition, function and co-morbidities if these are not volunteered) What may have made a difference to the decision? How did you see the alternatives for the older person? What was your experience of the older person being at home? What impact did that have on you?	Factors important in enabling them to remain at home (specifically ask about cognition, function and co-morbidities if these are not volunteered) What made a difference to them staying at home? How do you see the alternatives for the older person? What is your experience of the older person being at home? What impact does that have on you?

Table 2: Number of responses grouped by category

Category	Going well		Going badly	
	3 months	6 months	3 months	6 months
General/non-specific	43	37	27	11
Physical health	22	25	76	59
Mobility	34	22	18	17
Supports	27	25	15	8
Activities of daily living	17	6	11	2
Lifestyle	10	7	3	3
Mental health	0	3	7	8

Responses from the telephone interviews were grouped by topic. The number of times each topic was mentioned are given.

sion and were only assessed once, six declined to participate, four were younger than 65 years old, four were non-English speaking, three had severe dementia and one was undergoing terminal care. Telephone contact was attempted with all 159 older people, with 15 unable to be contacted, leaving 144 in the first part of this study.

The sample of 99 women and 60 men had a mean age of 81 years, and was frail with a mean score on the EFS of 8.8 (SD 2.5). Those not included were not statistically significantly different in terms of age, sex or outcomes at 12 months from those included in the study.

At the end of the study 105 older people remained at home and 39 had moved into aged residential care.

Telephone interviews

Due to the large number of participants, descriptive reporting of clustered responses was undertaken with notes from the telephone interviews. The number of responses classified in each category is shown in Table 2. In response to the question ‘what is going well?’ a number of topics emerged from the combined 3- and 6-month interviews: mobility issues (56 comments), community supports (52 comments) and physical health issues (47 comments). Activities of daily living (ADLs) were also mentioned (23 comments). In contrast, physical health concerns dominated the negative comments about ‘what is going badly?’ with 135 comments: pain, dyspnoea and urinary incontinence or catheters were frequently mentioned.

When asked ‘what would make a difference to you being able to remain at home?’ the largest number of answers (31 comments) concerned social and community supports, both formal and informal. Older people talked about the importance of having a spouse or family member for assistance with daily activities and company, as well as formal support services. These services were seen by many older people as key to their ability to remain in the community. Similarly, those who had already moved said that not being able to manage ADLs and not having appropriate support were key deciding factors.

Face-to-face interviews

Key topics from the telephone interviews were then used to guide the semi-structured face-to-face interviews with the group of 15 older people and the carer they chose to involve in the study (interviewed separately).

Role of the carer

The role of informal carers (classified as ‘supports’ in the telephone interviews) was a major theme arising from face-to-face interviews. Those who had moved to residential care often reported their informal carers as having poor health or too much stress or burden, while the carers of those who remained at home found caregiving to be worthwhile or rewarding. For example, this man who had moved into care talked about the stress on his wife, a factor which he felt had heavily influenced his decision to move:

... made her (*wife*) feel a bit uncomfortable, stressed out, ill at ease on occasion. I just didn’t keep my balance very well and this resulted in my wife being a bit concerned about what I was doing and whether I could be trusted to stop outside – and now all these things together added up to quite a degree of stress and illness on her part.

In contrast, a woman who remained at home reported the formation of supportive and reciprocal arrangements with friends and neighbours. She explained that a group of neighbours, including the interviewee, had cared for a woman while her husband was in hospital, and ‘she (*the neighbour*) did the same for him (*interviewee’s husband*) when I was in hospital’.

Carers also reported issues with the burden of care, and conflict between caring for the older person and other priorities such as family and work. One daughter whose mother moved into care reported:

... a lot of people assumed that, you know, she would live with me ... I just felt I’d end up really resenting her I suppose ... I’ve only just started my career after being a homemaker with my children.

Another daughter who had attempted to care for her parents at home before they ultimately moved into residential care talked about her parents’ care and how this conflicted with bringing up a family:

They needed twenty-four hour care. I’ve got to do this and myself, I’ve got a husband and four girls, [aged] twenty-four down to fourteen, so that would be full on and I thought well I’d enlist the help of my family, but then they realised they couldn’t do it because they’ve got their own family. It’s an impossible thing to actually be able to do – my sister and I did it for one night and realised that it was impossible.

For those who remained at home, carers also recognised benefits they had gained from caregiving, such as the satis-

faction this daughter found in being able to support her mother's wishes to remain at home:

If she can get the help she requires and she can live the rest of her life where she wants to be and where she's happy, that means more to me than anything else . . . her husband died in the family home and I think that's what she wants to do . . . I think if she had a fall and it was her last fall in her own home I think she'd be the happiest woman in the world.

Inevitability

For those older people who had decided to move into care and their carers, the sense of inevitability was a prominent theme. Older people reported that they had reached a point where their health or functional abilities, even with all the available supports, meant it was no longer realistic for them to remain at home. Factors which led to the move being considered inevitable included physical lifting, professional care in the community unable to meet their needs, and lack of family support. In contrast, for older people with similar problems (such as falls) who remained at home, the main difference was that they perceived support from either professional services or friends as available and sufficient. For example, when asked whether having falls was influencing her decision to remain at home, one woman responded, 'No, I don't think so, because I've got that contact; they (*the service provider*) come out and pick me up'.

Loneliness

Loneliness was also important, and a number of older people who moved into care reported having felt lonely, afraid or isolated at home. One older person reported:

I was lonely, for the first time in my life I felt lonely . . . when you've got that type of pain on your own it's quite frightening.

Physical health and hospital admissions

Further hospital admission also played a pivotal role in the decision to move. Those who had moved into care often had undergone one or more hospital admissions. They often reported that such admissions appeared unacceptable to hospital staff and that residential care was suggested to them as a way to avoid admissions. For example one woman who felt the decision to move into care had been taken out of her hands said, 'The hospital didn't want me any more. The hospital decided'; and another reported, 'I knew I couldn't stay at home and avoid going back and back to the hospital'.

Once they had been admitted, our group was at high risk of complications such as iatrogenic illness, which precipitated a cascade of illness, complications and functional decline leading to residential care admission. One carer described the course of events for her mother prior to her move into care. She had been an independent woman but a series of illnesses

and complications led to her not having the physical health, functional ability or confidence to continue living alone:

She had a leg ulcer that seemed to be quite persistent and not improving – morphine and immobility caused her to get constipated. She ended up with a whole lot of abdominal pain – she pressed her life link alarm and went to hospital by ambulance – then she got the diarrhoea bug – ended up being in hospital for three weeks.

Discussion

Frailty is an increasingly recognised issue among older people. In this study we examined the social, environmental and emotional factors in a cohort of older people following their discharge from hospital. This study follows our previous quantitative study [10], and focuses on the social context of frailty and residential care admission. Our cohort was frail, with a mean score of 8.8 on the Edmonton Frail Scale, and did not have the reserve capacity to cope with medical illness. This lack of reserve led to functional decline and patients required assessment and rehabilitation in a specialist geriatric unit.

Making the decision to enter residential care is a complex process and a life-changing event for the older person and their carers. Therefore, this study examined issues around the decision to enter aged residential care in depth, using two open-ended qualitative methods.

The role of informal carers was one of the most important factors described in this study. This could be either protective or a precipitating factor for residential care. The previous quantitative study was not designed to measure informal care or carer stress, but these issues were discussed frequently during both telephone and face-to-face interviews. Older people talked about their reliance on carers to remain at home, of their guilt about the burden they were placing on carers, and about feeling isolated and lonely. Meanwhile carers talked about how they managed to continue caring while they had their own health issues, other demands on their time such as career or family, the amount of time required, and, in contrast, benefits which could be gained from caregiving.

When such arrangements had broken down due to carer stress or burden, or the older person's needs being too great to be met by their care arrangements, the outcome was often a move to residential aged care. This finding is in keeping with previous studies where carer burden indices have been associated with increased residential care admission [18–20]. Shared care [21] and increased levels of social support [22] are associated with less institutionalisation.

In our quantitative study further hospital admissions were part of the predictive model for residential care admission. This finding is reinforced by these qualitative components of the study. Older people who had moved after a hospital

admission reported hospital staff viewed repeated admissions negatively and directed the older person towards care. Iatrogenic illnesses also had a major impact on the ability of older people to remain at home, with issues such as norovirus infection causing a cascade of functional decline, weight loss and loss of confidence leading to discharge to residential care.

The predictors of residential care admission are a complex mix of measurable factors such as function and comorbidities and less tangible interactions between older people, their social and community supports, and health professionals. This study highlights some of these interactions.

Acknowledgements

The principal author received a career development grant from the New Zealand Health Research Council to perform this research.

Key Points

- Social factors can be protective of, or precipitate the admission of frail older people to residential care.
- Carer stress or burden of care seen both from the point-of-view of the older people and the informal carers were key precipitants of residential care admission.
- Older people who moved into care reported loneliness more frequently than those remaining in their own home.
- Repeated hospital admissions, the health system's attitudes to such admissions, and iatrogenic illness can precipitate admission to residential care.

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