Exploring Perceptions of Quality of Life of Frail Older People During and After their Transition to Institutional Care

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This research focuses on the quality of life (QoL) of frail older people: those with severe physical and/or mental conditions or disabilities at the end of their lives. The research aims to contribute to understanding the meaning of QoL for frail older people, from the perspectives of older people themselves. Using a symbolic interactionist framework, we take a subjective, qualitative approach to QoL as a multi-dimensional concept, including social, psychological, emotional, cultural, spiritual and environmental dimensions.

There has been little research on QoL from the perspectives of frail older people, especially those with dementia and/or communication difficulties. To explore their life experiences we developed innovative methods of eliciting their views. The ethnographic research included six focus groups, naturalistic observation in four settings and observation and interviews with 52 individuals who had moved into care homes in the previous six months.

Summary of key findings

![We were able to elicit perceptions on QoL from older people with all types of physical and/or mental frailty, using methods tailored to different types of frailty, including innovative methods such as Talking Mats™.

Despite generally negative attitudes to frail older age and to life in care homes, both in wider society and within the care environment, we elicited perceptions of good QoL and observed frail older residents actively attempting to improve their quality of life.

The aspects that frail older people in care homes perceived as the main components of QoL clustered around four key inter-related areas: sense of self, the care environment, relationships, and activities. Having the opportunity to 'be oneself' in these areas was considered by the researchers to be key to QoL.

A variety of factors influenced QoL in positive or negative ways. These included responses to frailty; control and autonomy; responses to emotional needs; communication; continuities and discontinuities; gender, social class and ethnicity; the spiritual environment; and the cultural and structural contexts of the home.

Communication was a key theme. Being able or enabled to communicate verbally and non-verbally is essential for frail older people to express themselves, maintain a sense of self, form and maintain relationships, participate in interaction and activities, and make meaning of their experiences.

The participants experienced different degrees of continuity and discontinuity in being able to be themselves after transition to the care home. Continuities and discontinuities had different effects depending on the person, diminishing...
or improving QoL. Participants used various strategies to adapt to life in a care home, including distancing themselves from others, adapting their environment, having a friend, and making complaints.

Key aspects of quality of life

It is central to our conceptualisation of QoL in frail older age to recognise the diversity of frail older people. The findings point to the individuality of the people whose QoL we explored. We identify key areas important to our participants' lives and the factors that promoted or inhibited the quality of different aspects of their lives. The aspects that frail older people in care homes perceived as the main components of QoL clustered around four key inter-related areas that affect QoL: sense of self, the care environment, relationships, and activities. Having the opportunity to 'be oneself' in these areas was considered by the researchers to be key to QoL. We explore what 'sense of self' means in the context of a care home, and how much scope and support there appeared to be for people to be themselves.

Sense of self

Participants in care homes expressed their sense of self in a variety of ways and were enabled to do so, or inhibited from doing so, by a variety of means. Our participants had varying combinations of physical and mental conditions and disabilities, and almost half of them had a diagnosis of dementia. QoL was influenced by the meanings made by participants of their own and others' frailties and by the responses of others. Focus group participants stressed the importance of recognising older people's strengths as well as their frailties.

Participants' ability to feel 'at home' in the home was reflected in the extent to which they were able to be themselves, including how they dressed, items they chose to bring into the home, and control over personal space. Participants' not feeling 'at home' was reflected in frequent references to going home or only staying a short time, and in not accepting being in the home. For some their sense of being in the home was of a place where one was waiting to die rather than as a place to live.

Our participants expressed their sense of self through their personal appearance and possessions, and preferences for personal space. Their QoL was inhibited if they were unable to feel 'at home' in the home and to feel comfortable in expressing their sense of self positively. Other residents, care staff and visitors had a role in enabling participants to express their sense of self.

The care environment

People are active agents regardless of disability; having some control over daily living is central to maintaining a sense of self. The findings show ways in which participants lost control and were controlled in the care home environment but also ways in which they asserted, or were enabled to assert, control, choices or rights. The positive effects of moving to a care home included being looked after, and having cooking, cleaning and washing done by others; negative effects included loss of freedom of movement.

Participants' control over daily living was promoted or restricted by the environment and care regime of the home as well as by their physical and mental limitations. Care staff had a key role in supporting residents' autonomy. Some carers were attuned to interpret residents' non-verbal behaviour as signs that they wanted to take control. Those participants who were not supported in the most basic activity of control over continence expressed most anger and distress. Participants maintained and/or were supported in maintaining their sense of self through asserting control and choices, making complaints and adapting their environment. Care staff could enhance QoL through caring personal relationships with residents or inhibit it through lack of personal care and respect.

Relationships

Forming and maintaining personal relationships are fundamental to 'being oneself'. Moving into a home could be seen as a way of overcoming social isolation and improving QoL through social interaction and the opportunity to form new relationships. Conversely, there is a risk that people moving into homes become cut off from past associations with neighbours, friends and family. For some of our participants negative effects of moving to the home included loss of familiar company.

Participants' sense of self was enhanced or reduced through their communication and interaction with other residents and their reactions to others' behaviour. Although communication was often impeded by speech and hearing impairments, verbal and non-verbal communication and interaction did take place. Attitudes to other residents ranged from hostility and indifference to sympathy and friendship. Participants also expressed their sexual selves. Relationships with family enhanced QoL, particularly for the few residents who had a high level of involvement of spouses.
and/or relatives in their lives. Relationships with family members no longer alive seemed salient to the present QoL of people with dementia.

Activities
Participants maintained and/or were supported in maintaining their sense of self through engaging in meaningful activity. The daily routine of the home satisfied some residents' need for activity while others were bored and frustrated by hours of sitting without sources of stimulation. Some enjoyed watching the view or engaging in hobbies. Taking part in religious observance was important for some in and of itself and as an enjoyable activity involving singing and music. There was some evidence of staff engaging in specific activities with residents or giving personal attention designed to stimulate or entertain them. Going out of the care home was rare. Some residents enjoyed organised activities but others stressed the importance of being able to opt out of these.

Differences between groups
Participants' gender, social class and ethnicity affected their perceptions and experiences. Men and women had different ways of expressing concern about their appearance; women were more likely to form friendly relationships; and there were differences in how men and women spent their time. The Chinese participants' lives seem to have some distinctive qualities based on shared cultural interests, and for residents of the Jewish home there were some specific features based on their cultural and religious backgrounds. The relevance to QoL of feeling different from other residents because of social class background was evident in some cases.

Quality of life of frail older people
We developed innovative methods and successfully demonstrated that it is possible to elicit perceptions of QoL from older people with all types of physical and/or mental frailty, using different methods tailored to the individual. Despite the negative aspects of frail older age and life in care homes, we observed and elicited some perceptions of good QoL which allowed participants to be themselves. QoL was influenced in positive or negative ways. The key impacts were the older person's and others' responses to the person's frailty and strengths; being able to assert control and rights or loss of control and being controlled; validation or neglect of the person's emotional needs; the benefits of, or lack of meaningful communication and being able or enabled to communicate verbally or non-verbally; gains and positive continuities or losses and negative discontinuities from the transition to care home. There were advantages and disadvantages of gender, class and ethnicity. However, the spiritual environment and the cultural and structural facets of context in which frail older people experienced their lives in care homes also had key impacts on the individual's QoL and on differences in QoL between frail older people.

Our framework for understanding QoL of frail older people in care homes is summarised in Figure 1.

Policy implications
Policymakers and service providers have for many years accepted key principles for good practice. New systems for regulation of care that take account of residents' perspectives on QoL have been implemented in the UK. However, we found evidence of both good and poor practice. Our study showed that there were limited opportunities for professional carers to support older people to be themselves, develop relationships and have meaningful interaction. The study identifies positive impacts on QoL that can be used and promoted by policy makers, service providers and practitioners; conversely, it identifies negative impacts that should be avoided.

To promote QoL in frail older age, it is important that policy makers, service providers and professionals focus on the different priorities held by frail older people. This entails allowing or enabling frail older people to express their own preferences. Our findings show the importance of attending to verbal and non-verbal communication and emotion in expressing preferences. The methods used by the research team to facilitate communication through informal observation and intermittent conversation or through use of Talking Mats™ proved effective in enabling the frailest residents to express their preferences on factors that affect their QoL. These methods of exploring QoL with frail older people could be used by carers, practitioners, inspectors, family members and visitors.

QoL can be promoted by good quality individualised care. Care providers have an important role in enabling residents to maintain their sense of self, to communicate verbally and non-verbally, to exercise control and rights, to maintain and develop relationships, and to have meaningful activity and interaction within the contexts of institutional care settings.
About the study

The research fieldwork was carried out in three stages in two Health Board areas of Scotland (apart from two focus groups held in Bradford).

Focus groups

To identify QoL issues salient to older people, we held six focus groups in the community. These included a group of frail older people, family carers of older people with dementia, Asian men's and women's groups, and a women's friendship club.

General observation

Naturalistic observation was undertaken by the researchers in four care home settings. In each setting, observation was carried out in periods of two hours at a time during the day and a longer period at night, covering each day of the week and over 24 hours.

Guided conversations and individual observation

A sample of 52 residents was selected from six nursing homes and one residential care home. The participants included 41 women and 11 men. Their age groups ranged from 65-69 to 95-99; the majority were in the 75-89 age range. Twenty-four had a diagnosis of dementia. In one home three Chinese residents were interviewed by a Chinese-speaking interviewer; in another home which catered for Jewish people, five residents were interviewed. No residents from other minority ethnic groups had recently moved into homes in the study areas.

Views of frail older people on their experiences in care homes were sought during two or more sessions with each member of the sample. The participants' perceptions were elicited through their verbal and non-verbal responses. The first session with each individual began with observation and was used to identify one of three strategies for the next session: i) A guided conversation with an interviewer; ii) A guided conversation using Talking Mats™, a visual framework that uses picture symbols to help people with a communication difficulty; iii) A series of shorter individual observation and intermittent conversation sessions with people with severe cognitive difficulties. Ten interviews were completed by Joan Murphy using Talking Mats™. A video and booklet package about Talking Mats™ was produced.

Publications


Murphy, J. (2003) Talking Mats™ and frail older people: A low-tech communication resource to help people to express their views and feelings, Stirling: University of Stirling, Department of Psychology (video and booklet package).


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