

Exploring perceptions of quality of life of frail older people during and after their transition to institutional care (2003)

Susan Tester, Gill Hubbard, Murna Downs, Charlotte MacDonald, Joan Murphy

Summary of Research Results

This research focuses on 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 understandings of the meaning of QoL for frail older people themselves. 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 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.

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, making complaints.

Key aspects of quality of life

Sense of self

Participants expressed their sense of self through meanings made of and responses to their own and others' frailties and strengths, and through their personal appearance and possessions, and preferences for personal space. Their quality of life 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

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' agency. Those participants who were not facilitated to maintain control over one of the most basic activities, 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 quality of life through caring personal relationships with residents or inhibit it through lack of personal care and respect.

Relationships

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 quality of life particularly for the few residents who were able to maintain a sense of themselves as active members of their family through a high level of involvement of relatives in their lives. Relationships with family members no longer alive seemed salient to the present quality of life 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, engaging in hobbies or taking part in religious observance. Going out of the home was rare. Some residents enjoyed organised activities but it was important to be able to opt out of these.

Policy implications for quality of life of frail older people

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. 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, for example by using the methods developed by the researchers to facilitate communication, such as Talking Mats™. 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.

Exploring perceptions of quality of life of frail older people during and after their transition to institutional care

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Full Report of Research Activities and Results

BACKGROUND

The research focuses on quality of life (QoL) of frail older people: older people with severe physical and/or mental conditions or disabilities at the end of their lives. This period is perceived negatively in western societies, as seen in negative images and attitudes and in ageism. Critical gerontologists, from a political economy perspective, view older people as marginalised in the political and economic structures of society. Positive approaches to successful or active ageing have focused on the third age, thus further marginalising and stigmatising the oldest and frailest groups. These negative perceptions affect frail older people in the ways they are treated by society and by social policy, resulting in low expectations, loss of autonomy, and social exclusion. Frail older people in institutional care are further marginalised and excluded. This research examines how frail older residents may enjoy good QoL and maintain a positive sense of self despite generally negative attitudes both in wider society and within the care environment.

Research on the conceptualisation and measurement of quality of life has been unsatisfactory, both theoretically and methodologically (Birren and Dieckman 1991). QoL studies of older people have been mainly on health-related QoL (Bowling 1998; Farquhar 1995). However, there has been some development of a broader conceptualisation of QoL including social, psychological, emotional, cultural, spiritual and environmental dimensions (Birren et al 1991; Whitehouse 1999). This research uses these dimensions in approaching quality of life as a multi-dimensional concept. Since it is difficult to formulate a generic definition of QoL (Hughes 1990: 49), models specific to particular groups of older people, for example people with dementia, are being developed. In this research we develop a conceptualisation of quality of life for frail older people in care homes.

There has been little research on QoL from the perspectives of frail older people, especially those with the most severe disabilities and those with whom communication is difficult, who are often excluded from research (Farquhar 1995). Most QoL studies of older people have been objective and quantitative. Whilst recognising the value of both quantitative and qualitative and combined approaches, this research takes a subjective qualitative approach to quality of life. It starts from the view that ‘Quality of life is a dynamic interaction between the external conditions of an individual’s life and the internal perceptions of those conditions’ (Browne et al. 1994: 235). This approach assumes that feelings and judgements

about life are ‘intrinsic, subjective matters’ Exploring perceptions of quality of life of frail older people during and after their transition to institutional care

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Key findings

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- 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.
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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. 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, for example by using the methods developed by the researchers to facilitate communication, such as Talking Mats™. 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.

(Farquhar 1995: 1440) and that an individual's perception of good quality of life is embedded in the context of personal values, goals, talents, histories, and life experiences (Faden and German 1994: 542).

We elicit perceptions of quality of life by exploring the life experiences of frail older people, including those with dementia and/or communication difficulties, who moved into care homes in the six months prior to participation in the study. Research on the effects of transition to institutional care on QoL is ambivalent (Oldman and Quilgars 1999, Reberger et al. 1999). Continuities and discontinuities with life before the move may have positive or negative impacts and residents develop strategies for adaptation to the new environment (Reed and Roskell Payton 1996).

The research addresses key current policy issues of quality of life and quality of care. We distinguish quality of life from quality of care while recognising that quality of care can contribute to quality of life in institutional care. Research over many decades has highlighted negative aspects of care and of life in residential and nursing care homes (Peace et al. 1997). Recent policy emphasis on quality assurance and outcomes of care has promoted qualitative models for evaluating quality of life in care homes, using the basic values of privacy, dignity, independence, choice, rights and fulfilment, and drawing on the subjective experiences of residents and staff (DOH/SSI 1989, Kellaheer 1998). In England and Wales and in Scotland national care standards have been introduced to implement such principles and values within new systems of inspection and regulation of care that take account of residents' perspectives on quality of life.

OBJECTIVES

The main aim of the research was to contribute to understandings of the meaning of QoL for frail older people, from the perspectives of older people themselves. The research had five main objectives:

- To develop a new conceptualisation of QoL in frail older age, giving a central place to the views of frail older people.

This objective was addressed and fully met by identifying, through focus groups, observation and interviews with older people, the aspects of their lives that older people perceived as the main components of QoL and the positive and negative impacts on these. We developed a framework for understanding QoL of frail older people in care homes (Figure 1, Annex 1).

- To develop innovative methods of eliciting frail older people's views on the meaning of QoL.

This objective was addressed and fully met. We developed innovative methods tailored to different types of frailty, including Talking Mats™. A video and booklet package on

Talking Mats™ was produced to facilitate use of this method of helping older people to express their views.

- To examine ways in which the transition to institutional care affects QoL in frail older age.

This objective was addressed and met by exploring different aspects of participants' lives before and since the move into institutional care, their experiences of positive and negative continuities and discontinuities, and strategies for adapting to life in a care home. It was not always possible to discuss these issues with people with cognitive impairments. A research design that included eliciting views before and after the transition could meet this objective more fully.

- To identify and explore inequalities (by social class, gender, ethnicity) in experiences of QoL during and after this transition.

This objective was addressed and partly met through observation and interviews, particularly in relation to gender differences. Social class, while more difficult to establish, was relevant to QoL in some cases. We included three Chinese participants and five residents in a home catering for Jewish people, whose lives had distinctive qualities. No residents from other minority ethnic groups had recently moved into homes in the study areas.

- To examine links between QoL in institutional care and quality of care from the perspective of frail older people.

This objective was addressed and fully met through naturalistic observation and through individual observation and interviews exploring the care environment.

METHODS

The project took an ethnographic approach to exploring the meaning of quality of life (Hammersley and Atkinson 1995), using a range of qualitative observation and interview methods. We used an interactionist approach, trying to understand the symbolic worlds and shared meanings of frail older residents and the negotiation of meanings through social interaction (Blumer 1969). The study's central focus on understandings of the meaning of quality of life, from the perspectives of older people themselves, posed methodological challenges. We aimed to include people with all types of physical and/or mental disabilities or conditions.

Our key methodological objective was therefore to develop innovative methods of eliciting frail older people's views on quality of life. In developing these methods we engaged with broader ethical issues concerning research with frail older people, consistent with the British Sociological Association guidelines (BSA 2002). We addressed thoroughly the issue of gaining informed consent from frail older people who, for reasons of physical or mental disability, may have had difficulties with understanding what was required of them and/or with completing written consent forms. We used a process of continuously negotiated consent (Hubbard et al. 2001).

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

In preparation for the observation stage, a pilot study of observation methods was undertaken by the research fellow, in collaboration with Ailsa Cook, an ESRC-funded PhD researcher. This showed the importance to quality of life of non-verbal communication (Hubbard et al. 2002).

Naturalistic observation was then undertaken 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 in each home. Observations were mainly carried out in public areas of the homes, but some participants also agreed to the researchers observing in bedrooms. The researchers wrote up detailed fieldnotes as soon as possible after the observation.

Guided conversations and individual observation

A sample of 52 residents was selected from seven care homes (six nursing homes and one residential care home). The participants included 41 women and 11 men. Their basic characteristics (from questionnaires completed by care home managers) are listed (Table 1, Annex 1). Their age groups ranged from the 65-69 group to 95-99; the majority were in the 75-89 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 of QoL and the transition to institutional care were elicited through participants' verbal and non-verbal responses during two or more sessions. 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™. The interview and observation methods are discussed further by Hubbard et al. (2003c); and the Talking Mats™ method by Murphy (2003).

The process of data analysis was continuous throughout the fieldwork and analysis stages. The qualitative data software package NUD*IST 4 was used for categorisation and data handling, and to facilitate analysis. The field notes from focus groups and observation and the interview transcripts were coded using frameworks developed and built upon as each stage progressed. From interviews using Talking Mats™, video recordings, field notes and digital photographs of completed mats were analysed using cognitive mapping (Jones 1985); these data were subsequently incorporated into the main findings. At each stage the data were examined for themes, using an iterative process (Hammersley and Atkinson 1995:205). The researchers regularly discussed emerging themes before exploring them further, thus ensuring a rigorous approach to analysis.

RESULTS

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: 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.

Developing frailties and the transition to institutional care often entail threats to self, autonomy and relationships (Bruce et al. 2002; Kitwood 1997). 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, making complaints.

The spiritual environment and broader cultural and structural contexts of the care homes and their residents also influenced quality of life. Cultural facets of context include the local culture of the group of residents and of the culture of care operating within specific homes; structural facets of context are framed by resources, staffing, and distribution of public and private space (Gubrium 1995; Hubbard et al. 2003a: 109-10).

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.

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. There was general acceptance and tolerance of the need to fit in with rules and timetables. However, the loss of freedom expressed in terms of feeling controlled or under surveillance provoked anger, frustration or sadness in some participants. Others expressed a valuing of opportunities to be independent and there was some evidence of people making a conscious effort to adapt the environment to suit themselves. Some activities such as

smoking were controlled by staff, although there were examples of residents asserting themselves and ignoring such controls. 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 facilitated to maintain control over one of the most basic activities, 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.

The findings show that participants, including those with dementia, had a sense of self in relation to others. They were able to take on the role of others to interpret behaviour, make meaning of it and react to it (Hubbard et al. 2002: 159). Some residents reacted to others' behaviour with hostility, labelling them as 'mental' or 'funny types' and distancing themselves from these roles. For example, groups of residents colonised particular lounges to avoid those labelled as 'mental'. In this way they projected their 'self' as not 'mental' (Hubbard et al. 2003a: 108-111).

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 through their dress and appearance, humour, flirting and affection (Hubbard et al. 2003a). 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. One way of supporting older people with dementia in retaining a sense of self is to encourage them to talk about their life history, building on the strengths of emotional memories of the self (Mills 1997).

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 from the window 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. Regular visits to family homes were very important. Very few participants spoke about other kinds of outings except as something they would like rather than as something which happened. This meant that involvement in the community and ordinary activities such as going window shopping or going for a pint were no longer possible. Some residents enjoyed organised activities in the care home 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. Talking MatsTM proved an effective method of gaining views that a frail older person may not otherwise be able to communicate. We suggest that enabling people with severe communication difficulties to express their views and choices can in itself enhance quality of life. We explored different strategies for eliciting the views of people with dementia and found that individual interviews and observation were 'meaning-making occasions' for them (Hubbard et al. 2003c: 360).

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. The key impacts on QoL 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, Annex 1.

Policy implications

Policymakers and service providers have for many years accepted key principles for good practice. New systems for inspection and 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 verbal and non-verbal communication in expressing preferences and emotions. The methods used by the researchers to facilitate communication through informal observation and intermittent conversation or through use of Talking MatsTM 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.

ACTIVITIES

We attended all the national meetings of the ESRC Growing Older programme. We presented papers and posters at four annual British Society of Gerontology (BSG) conferences, and at annual Journal of Dementia Care conferences. We presented papers at international gerontology conferences in Vancouver, Chicago, Boston, Barcelona and Murcia. In Boston our paper contributed to the GO Programme symposium. This dissemination activity has been well received and the project has attracted much interest.

Our research advisory group included policy makers, representatives of voluntary organisations and user groups, nursing home and social work practitioners, and academics. The group met five times during the project. We gave regular progress reports to the group, who offered extremely valuable advice on research design and methods and on draft publications.

OUTPUTS

Our publications include three refereed journal articles, a book chapter, and three other journal papers. Further publications are in preparation or planned. We have presented seven papers and six posters at national conferences and five papers at international conferences.

There are also two innovative dissemination outputs to highlight. To facilitate communication between frail older people and care staff or relatives, we produced a video and booklet package to explain and demonstrate the use of Talking Mats™ (Murphy 2003). The research team, together with Ailsa Cook, also developed a multi-media interactive CD-Rom (Hubbard et al, 2003b). The CD-Rom, incorporates video, audio, text and film stills; it was produced by a multi-disciplinary team including social researchers, film producer and film crew, actors, and multi-media developers. It presents research findings through dramatisation of observation in care homes. The CD-Rom was devised as an innovative dissemination strategy that is accessible to non-academic as well as academic audiences.

IMPACTS

Following dissemination to date there has already been interest in and enquiries about the research from a wide range of research users. The research advisory group included members involved in developing new systems of regulation and care standards who have drawn on the project. It is expected that our methods of exploring QoL with older people with all types of frailties will contribute to practice by care providers and inspectors. Some staff from local nursing homes have received training in the use of Talking Mats™; further training is planned. The project has been selected to contribute to a GO programme seminar for policy makers in January 2004.

FUTURE RESEARCH PRIORITIES

- Further development of our techniques for identifying the most suitable method of eliciting perceptions on quality of life for older people with different types of frailty.
- Action research that would engage with care home staff and residents in trying to achieve better outcomes for residents through applying the approaches used in the study to elicit views and preferences and respond to them.
- Further exploration of the transition to care home, discussing quality of life with older people before they entered the home as well as on several occasions after the move.
- Further development of the theme of differences between groups in quality of life, focusing on older people from minority ethnic groups in care homes, drawing on a wider geographical area to identify an appropriate sample from different groups.

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ANNEX 1

Table 1. Characteristics of Interview Participants

People interviewed using Talking Mats™ are identified with ™ after their name.

	Home ⁱ	Pseudonym	Gender	Age group	Minority ethnic group	Dementia ⁱⁱ	Previous setting
1	E	Joseph Kaplan	m	75-79	Jewish	Yes	own home
2	E	Hannah Lewis	f	90-94	Jewish	Yes	own home
3	D	David McIntyre	m	90-94		Yes	hospital
4	D	Nancy Dunlop	f	75-79		No	own home
5	E	Sarah Stevenson	f	85-89	Jewish	Yes	care housing
6	B	John Williams	m	75-79		No	own home
7	B	Douglas Mills	m	65-69		N/a ⁱⁱⁱ	own home
8	B	Harry Fraser	m	90-94		No	own home
9	D	Isabel Gray	f	85-89		No	own home
10	B	Chia Tai-Meng	m	80-84	Chinese	Yes	own home
11	B	Foo Geok-Jin	f	70-74	Chinese	No	own home
12	G	Jane Campbell	f	80-84		Yes	hospital
13	G	Maureen Stone	f	70-74		No	hospital
14	G	Eleanor Black	f	90-94		Yes	hospital
15	G	Jeanette White	f	65-69		No	hospital
16	G	Elsie McKay	f	85-89		Yes	hospital
17	G	Freda Jamieson	f	90-94		Yes	hospital
18	G	Betty Morrison	f	85-89		Yes	hospital
19	G	Flora Gray™	f	70-74		No	hospital
20	G	Abbie Howard	f	75-79		Yes	hospital
21	F	May Buchanan	f	85-89		No	hospital
22	F	Anna Murray	f	75-79		Yes	hospital
23	F	Betsy King	f	75-79		No	hospital
24	F	Edna Wright	f	95-99		No	hospital
25	C	Bill Gallacher	m	70-74		No	hospital
26	C	Amy Logan	f	80-84		No	hospital
27	C	Christina Strong	f	85-89		No	hospital
28	C	Frank Carswell	m	95-99		No	hospital
29	C	Rachel Gibb	f	85-89		Yes	hospital
30	C	Marjorie Stuart	f	85-89		Yes	other home
31	D	Hugh Lawson	m	80-84		No	own home
32	C	Maira Nelson	f	75-79		Yes	own home
33	C	Eunice Knight	f	85-89		No	hospital
34	D	Susan Strang	f	70-74		No	other home
35	D	Doreen McCall	f	75-79		No	own home
36	D	Frances Thomson	f	80-84		Yes	own home
37	A	Clara Peterson	f	80-84		Yes	other home

38	A	Diana Moffat	f	75-79		Yes	hospital
39	D	Irma Davidson	f	85-89		No	own home
40	D	Janet Oliver	f	80-84		Yes	hospital
41	F	Morag McVey TM	f	90-94		Yes	hospital
42	F	Gordon Miller TM	m	75-79		No	hospital
43	F	Judith Strang TM	f	85-89		No	hospital
44	G	Louise Cook TM	f	85-89		Yes	hospital
45	G	Peggy Burns TM	f	75-79		Yes	hospital
46	G	Barbara Smith TM	f	85-89		No	other home
47	G	Ruth Taylor TM	f	75-79		Yes	other home
48	F	Ellen Young TM	f	80-84		Yes	sheltered housing
49	E	Miriam Rees	f	80-84	Jewish	No	hospital
50	E	Denis Samuels	m	85-89	Jewish	No	hospital
51	F	Aileen Gordon TM	f	70-74		No	hospital
52	B	Li Siew-Yen	F	80-84	Chinese	No	own home

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- ⁱ A nursing home charging 50% more than basic Council rate
 - B residential care home charging basic Council rate
 - C nursing home charging slightly more than basic Council rate
 - D nursing home charging basic Council rate
 - E nursing home charging 20% more than basic Council rate
 - F nursing home charging basic Council rate
 - G nursing home funded by NHS

ⁱⁱ this information was supplied in a short questionnaire completed by staff at the Home. The question asked was 'Does the resident have a medically diagnosed dementia?'

ⁱⁱⁱ information not provided in this case but assumed not to have dementia based on interview response.