

Quality of life in the care home: a qualitative study of the perspectives of residents with multiple sclerosis

Running title:

QoL in care home residents with MS

Keywords Quality of life, care homes, qualitative research, multiple sclerosis, care home residents

Abstract

Purpose

Care home residents with multiple sclerosis are more physically dependent than the average resident. However, little is known about their quality of life. We investigated the experiences of residents with multiple sclerosis using qualitative research methods, and developed a conceptual model of quality of life.

Methods

Twenty-one people with multiple sclerosis (age range 43-80 yrs) residing in a range of care homes were interviewed. The interviews were transcribed verbatim and analysed using the constant comparative method.

Results

Four core model domains were identified: 1) *What the care home means to the residents*, 2) *Self*, 3) *Environment* and 4) *Relationships*. Some residents reported that care homes can relieve the burden on family, address specific environmental issues regarding safety, and act as a form of social support. However, some reported isolation and difficulties adjusting to life in the care home. Having access to rehabilitation strengthened the feelings of independence within the care home.

Conclusions

Quality of life is a broad, multidimensional construct for residents with multiple sclerosis. Quality of life measures for residents with multiple sclerosis should incorporate broad domains, including environmental factors. The conceptual model highlighted several areas for improving quality of life of residents with MS, including more involvement of family members, encouraging independence by providing access to rehabilitation, and providing support in the transition process.

Introduction

Approximately 5% of people with MS will eventually need long term care provided in a care home [1] (a residential setting that provides accommodation with nursing and personal care). Although this is a minority, people with MS and their carers express considerable concern about “going into care”. Over one third of residents with MS are depressed at admission [2]. Social isolation of mentally alert MS residents in facilities primarily for older residents, and lack of staff training in handling the range of MS complications have been highlighted [3].

Despite this, there has been limited research examining the experiences of care home residents with MS. Little is known about how these residents view their “quality of life” (QoL), nor what aspects of life they now most value. Understanding residents’ QoL is important because: 1) QoL is a key concept in health care [4], 2) Health and social care professionals that urge changes in living conditions have responsibility for residents’ QoL [5], 3) Where it is the individual’s preferred choice, care within an individual’s home (home care) is promoted as an alternative to residential care [6,7]. To avoid recreating within home care the aspects of care homes that most negatively impact on QoL, we need to better understand QoL [5].

There is no agreed definition of QoL [8]. It can go by a range of other names, such as well-being, satisfaction with life or happiness. In health services research, the term is frequently used interchangeably with health-related quality of life (HQoL), and measurement of HRQoL is concerned with the individuals’ reports on the impact of the disease and its treatment on different domains of their daily life and health

experience [9, 10]. Most of these measures take the view that HRQoL is a multi-dimensional construct encompassing dimensions such as physical, psychological and social functioning. For residents, a much broader conceptualisation of QoL encompassing the physical, psychological, social and environmental domains [11] is likely to be appropriate. Spending time with family and friends [12], good relationships with staff and peers [13], having autonomy [14], privacy and security [5], have all been associated with good QoL in residents with MS living in care homes. However, the views of residents with MS, who are younger [15], more physically dependent [15], and less cognitively impaired [15], have not been widely studied. We used qualitative research methods to identify QoL factors that residents with MS felt were important.

The aim of this study was to explore how residents with MS perceive their QoL in the care home, and to develop a conceptual model of quality of life for care home residents with MS.

Methods

Participants and settings

Care homes offering nursing care and/or personal care, with both high and low proportion of MS residents were approached. Participants were recruited via their care home managers who identified potential participants, and forwarded the information about the study to participants who were interested in taking part in the study. Homes were within a 100 mile radius of London, UK. They differed in size,

setting (urban/rural), and organisation type (large vs. independent homes). The Deprivation Index [16], a UK government produced area level measure of deprivation that includes assessments of income, employment, health and education, and the Care Quality Commission scores [17], care quality scores given by the Care Quality Commission which is an independent regulator of health and social care standards in England, were obtained. Participants with a range of age, gender and disease duration were recruited using non-probabilistic purposive sampling. Ethical approval was obtained for the study before recruitment of participants.

Procedures and Data Collection

Participants were interviewed individually in their care homes. Informed consent was obtained from all participants. Prior to interview, the cognitive ability of the resident was determined by the researcher (SB), reflecting on conversation during the consent process and their general demeanour [18], though no formal cognitive evaluation was undertaken at this stage in order to be as inclusive of participants as possible. Participants who could not give consent and those who could not follow the interview questions did not take part. The interview began with open-ended questions on their familiarity of the concept of QoL (“Are you familiar with the concept of quality of life?” “What does quality of life mean to you?”) their QoL in the care home (“How would you describe your quality of life here in the care home?” “What are the things that are important to your quality of life now in the care home?”), and factors affecting their QoL (“What are all of the things you consider when you think about how things are going in your life?”, “What are the things that you feel are absolutely essential for you to live a good quality of life here?”).

Both positive and negative aspects of QoL were identified. Questions and probes for the semi-structured section of the interview focused on a broad set of themes derived from a literature review such as relationships and recreational activities [19;20;21]. The themes were chosen to elucidate ideas about privacy and dignity, grief and loss, and participation and autonomy [22]. The interview guide was refined as new themes were brought up by the residents.

Analysis

Each interview was recorded and transcribed verbatim. Data collection and analysis were conducted concurrently until data saturation was reached [23]. That is, we finished interviewing residents when we were sure that the same instances of data was being repeated over and over [23] and no new 'experiences' were being reported by participants regarding their quality of life. Alternating between collection and analysis allowed confirmation of coding categories while they were being developed [24]. The transcripts were read repeatedly by two investigators (SB and AR). These two investigators independently coded the transcripts using open coding, by assigning codes to the text based on words or phrases that captured meaning in the data [24] (figure 1). Figure 1 gives an example of the coding process. Step 1 shows the example of *open coding*, and examples of quotes under the open code of "Standing up for yourself" and "Dependency". In Step 2, consensus of open coding categories was refined using *axial coding*, where open codes are organised according to conditions that give rise to it, and its context [24]. Figure 1 shows that the open codes of "Standing up for yourself" and "Dependency" are combined as

“Self-concept”, an axial code which refers to how a person views aspects of their persona in terms of positive and negative aspects. In Step 3, *selective coding*, core categories are created that bring together conceptually coherent axial codes [24]. In the example in Figure 1, the selective code of “Self” was formed through combining four axial codes: “Self-Concept”, “Control”, “Multiple Sclerosis” and “Life Satisfaction”. Each investigator coded each incident of data into as many categories of analysis as possible, each time consciously comparing an incident for coding with others previously coded (incidents of data and their categories) [23]. This constant comparative analysis process ensured that categories were broken down into the smallest possible meaning, and allowed the validation of codes through identification of any negative cases. After coding each transcript, discussions were held between the investigators regarding the emerging categories, as well as the plausibility of the categories against the transcripts, and consensus was reached. This process was repeated for each transcript, and the emerging categories were continually checked for adequate “fit” with the data. The data was analysed with the aid of Winmax, a qualitative data analyses software.

Insert figure 1 about here

Results

Thirty-seven individuals with MS were identified. Twenty-one residents from 10 care homes were interviewed. Recruitment stopped after 21 participants when data saturation was reached. This sample size is comparable to other studies using

similar methodologies [25]. Five of those who could not complete the interview had speech problems or could not communicate. Eleven could not follow the interview questions. Age, years since MS diagnosis, years in care home, and marital status did not differ between interviewed residents and those who could not be interviewed (all p 's > 0.05). Interviews ranged from 28 minutes to 2 hrs. All 21 participants were wheelchair users (table 1). The care homes spanned a wide range of settings, organisations, and Care Quality Commission scores (table 2).

Insert tables 1 and 2 about here

Conceptual Model of QoL

Open and axial coding of transcripts revealed a comprehensive list of themes that related to the concept of QoL. Selective coding further revealed four main model domains: 1) *What the care home means to the residents* 2) *Self* 3) *Environment and* 4) *Relationships* (figure 2).

Insert figure 2 about here

1) What the care home means to the residents

This core theme related to the residents' attitudes towards living in the care home. It was frequently mentioned and often repeated by the residents. The subcategories were: "Acceptance of living in the care home", "Decisions on moving to the care home", "Missing their own home".

Residents' attitudes towards their care homes differed considerably. Some residents acknowledged that the care home was the best place to cope with their disability. Although they missed their own homes, they were more willing to highlight positive aspects, such as being "looked after":

'Well I didn't like the fact that I was gonna go into a nursing home but there wasn't any choice really, you know, you've got to be safe, you've got to be realistic' (female, aged 59)

However, others felt they had no control or choice about their living arrangements. They continued to miss their own homes and previous roles, and indicated a strong desire to leave the care home:

'The most important thing is for me to go home. This is not a home. In a month, I'll be in that wheelchair and I'll be gone.' (male, aged 58)

The third view was of ambivalence and indifference. These residents demonstrated some acceptance of their living situation, but also acknowledged their lack of belonging in the care home:

'I don't enjoy it, I don't like it, but you have to make the best out of...the best you can. I mean from my wife's point of view is, is that I think for her... it's not exactly for her it's, it's er I can have a quality of life if you like up there in one of those little rooms, listen to the radio or watch the TV, go to bed or whatever.' (male, aged 56)

2) Self

This domain reflected the residents' views of themselves, and their own strategies for living in the care home. Subcategories included "Self concept", "Control", "MS" and "Life Satisfaction". "Self concept" referred to negative feelings, such as feeling hopeless, worthless, or irritable, and positive feelings, such as enjoying their own company, feeling confident, and maintaining a strong sense of identity irrespective of their living arrangement:

'I think it's given me more confidence because one must stick up for oneself, and one could become institutionalised in here' (male, aged 56)

"Control" referred to day-to-day decision-making, being in control over their affairs and maintaining independence:

'I still got things I mean I have to achieve, but at least here, so I have to work on it. Work on being able to write a letter, I've got my phone directory on the telephone to sort out.' (female, aged 61)

This included the use of physiotherapy, which was commented on by many to be a key aspect of their qol if they were able to have access to it:

'when I was out living with my parents I think I had a physiotherapy treatment, physiotherapy once a fortnight, well what use is that there's just no use. So I mean here I have it 3 times a week which is fantastic' (female, aged 45)

“MS” related to the impact of MS on their life in care home. MS symptoms such as pain, fatigue, mobility restrictions and their ability to cope with MS, were mentioned as having a negative impact on their life in the care home:

I: Could you tell me a little bit then about how you spend your days generally?

R: Mostly in bed if I can, I've got a chair....but I have those chest straps on to keep me in the chair sitting up straight and that head thing on and it's ... uncomfortable – I feel very restricted. And with this groin strain some days I sit in the chair for 3 hours....and say I'll go down for one of them activities, I can't look that way and I have trouble with me neck being so stiff. I can't get round that way. Me most comfortable is in the bed.' (female, aged 59)

“Life satisfaction” referred to contentment with life. For example, many residents spoke about making the best of their situation:

'My quality of life is ok, compared to my past life it's as best as it could be really.... I could be sleeping under a bush somewhere. So it's better, there is no comparison really because I got a nice warm, dry bed to crawl in to so everything is fine, I got food and that's fine, you know I got I got ehmm... my cd player and a TV and everything I need so I'm quite happy and that's it really.' (male, aged 58)

Where residents continued to mourn the loss of their previous activities and roles, this had a negative impact on their QoL:

'I can't get to do the things that I want to do like, I haven't been to the theatre in over two years and that's my love, I love the theatre and it makes it difficult going with (name) cos

(name)'s got to look out for me and I don't like that, I don't want to be a burden on someone.'

(male, aged 47)

3) Environment

This broad domain included the various environmental aspects of the care home, and included the subcategories of "Physical environment of the care home", "Engagement in Activities", "Privacy", "Feeling safe" and "Personal care".

"Physical environment of the care home" included the overall comfort (e.g. noise, temperature, furniture, and space), meals served, and accessibility of belongings:

'I am thinking one huge advantage of this place, as it was purpose built so it's not, a really old building trying to convert it, but that cannot work every time I'm sure, erm, but having been purpose built so there's a lot of space erm, the rooms have you seen, the rooms? They're very good sizes.....Yes the bedroom is excellent and the bathroom.' (female, aged 45)

"Engagement in Activities" referred to trips out, participating in worship and hobbies, being involved in decision-making within the care home, and conversations with others (quote 11).

'Trips out to pubs for a meal and you know, and it's lovely cos some people would look down their noses at it. Erm but they'd be that sort of person, anyway. You've got to, you've got to join in. Er I mean they're, they're marvellous here. Um, with er you know all the things we do' (female, aged 58)

Feeling bored or “stuck” in the care home, and not having something to look forward to, all had a negative impact on QoL. “Privacy” related to respect for their privacy, and being left alone if they wished. “Feeling safe” in the care home was mentioned by all residents, and was one of the most salient aspects of care home living. Residents mentioned they felt safer, as they now have access to help should they need it (e.g. if they fall). Safety also related to the ability to move around using their wheelchairs, as opposed to feeling unsafe walking in their own homes. This made them feel more autonomous and independent. This subcategory also encompassed the general feeling of security, and reduced vulnerability:

INT: ‘Could you tell me what you mean by safe?’

RES: ‘Well I would say as a main priority I am being watched over, regular, regular food, regular medication which I... but that that is 24/7.’ (male, aged 60)

“Personal care” contributed negatively to QoL when the carers were rushed, or when the residents had to wait a long time for assistance:

‘They take a long time to answer and I keep saying as soon as you hear the bell you should go to whoever it is ‘ (male, aged 47)

4) Relationships

Three subcategories were identified within this domain: “Relationships with important others”, “Interactions with care staff” and “Relationships with other residents”.

“Relationships with important others” included time spent with family and friends, and

their support and involvement in care. Some residents missed their partners and felt abandoned:

RES: 'all I want to do is go home.'

INT: 'Yeah, do you ever go home, do you ever take a trip back?'

RES: 'No, no, I want to but it's not in my wife's vocabulary.' (male, aged 58)

However, other residents mentioned improved relationships and a sense of relief at being less of a burden on their families:

'Well yes, I mean erm I'm glad in hindsight because the last thing I would want to do is er lumber them with me, I'm sure they would've erm been happy to look after me, but I don't think they would like to have to, er tend to me as carers here do, erm I think that's another aspect that they shouldn't see their father and in some situations I'd get into.' (male, aged 63)

"Interactions with care staff" included satisfaction with care they receive, continuity of care, being able to communicate well with care staff, and being respected as individuals. Having a friendly relationship with the carers, as well as the carers' understanding of MS, were important for all residents:

"but people who are actually paid to be, to look after us should know, but they don't, and also because ok, I could just sit here and you wouldn't know if there was anything wrong with me, apart from being stupid, I don't have any look of physical disability and because I don't show a disability therefore, it's ok there's nothing wrong and they don't understand that I can't pick things up. So it's the little things.' (male, aged 47)

“Relationships with other residents” included interactions that provide social support:

RES: 'its quite fun in this place....erm there's a few of us that get together you know.'

INT: 'A few of the other residents?'

RES: 'Yeah, two of the other, well one in particular, this (name) we have a laugh, then there's (name) she's a laugh' (female, aged 58)

However, problems and lack of interaction with other residents were also mentioned.

This lack of interaction was either deliberate (i.e. wanting to spend time on their own), circumstantial (the home predominantly consists of people with severe cognitive difficulties), or attributed to their MS symptoms (e.g. pain or fatigue) impacting on their ability to socialise:

'That's another big thing, don't put me into a place where a lot of the people don't even have the ability to eat the same as me and we have people with ages of mental ages of 3 and we have old people which actually when you talk to them they can be quite intelligent or quite, knowledgeable but most of them actually aren't....I don't mind living on my own I just, there's no one that I, I'm being big headed cos there's no one here I can actually talk to that's on the same level' (male, aged 47)

Issues surrounding peer residents significantly impacted their QoL and their ability to feel as part of a community:

RES: 'The first floor mostly for people who are bed ridden and this is the floor for the aged and frail people up here which meant that most of the activity stopped so you're in a room

most of the day.'

INT: 'So it's actually quite a change from when you first came here?'

RES: It is because some days I don't even have a short conversation with anybody, some days.' (male, aged 78)

At the same time, many residents with MS also displayed downward social comparisons by comparing themselves favourably to other residents:

'I'd say it was a good life compared with what other people have to put up with in here, I'm thankful..... I'm not, I'm not um, dependent or relying on, other people giving me things to do.' (female, aged 64)

Discussion

In care home residents with MS, QoL is a multi-dimensional construct consisting of four core categories (*What the care home means to the residents, Self, Environment and Relationships*). Previous studies have also shown that QoL in the care home is complex [5] and is closely connected to their residential situation [e.g. 26]. The four core categories also map onto the International Classification of Functioning, Disability and Health (ICF) components of Body Structures and Functions, Activities and Participation, Personal and Environmental Factors, which covers a range of domains on functioning, from both an individual and societal perspective [11]. However, environmental factor in particular is a concept that can be overlooked in traditional HRQoL measures [27]. This study demonstrates the importance of this construct in QoL of residents with MS. It also suggests that traditional HRQoL

measures that mainly focus on the individuals' perceptions of daily functioning and well-being in physical, social, and psychological domains [28] are unlikely to capture the broad impact of residential living on QoL in people with MS.

Similar findings have been reported in studies of older individuals who reside in care homes. For example, in older residents, attitude to residential living is also central to thriving in a care home [29, 30]. Mourning of losses of home, important others and roles, physical ability, independence and freedom has also been reported by older residents [31]. Some studies have also demonstrated that the care home serves to relinquish any feelings of burden they might have felt on their family [32]. In our study, residents with MS living with those with dementia or behavioural problems, reported that this negatively impacted their QoL. This is in line with previous findings from cognitively intact older residents [33]. Many residents with MS spoke of the importance of social support provided by other residents in the care home to their QoL, these included other residents with MS but also other residents of the same age and gender. The value of support from other residents has been reported in several past studies [34]. Future research is needed to more specifically identify the characteristics of residents who could increase the QOL of MS residents, for example, characteristics such as similar age, educational background, levels of disability/dependence, mental alertness and mental health. However, some MS residents also reported isolation from other residents. If residents are unable to develop meaningful relationships with other residents, the carers become the resident's primary source of interaction. This is especially so when family members are unable to visit often. Thus the carer's role in influencing residents' QoL is magnified [35], and suggests that maintaining continuity of care staff is essential.

Some differences from previous studies were also apparent. For example, previous findings have suggested that moving to and living in care homes can undermine one's identity and sense of self [36], this was not always apparent in MS residents. This suggests that a complete loss of identity does not necessarily result [37].

The variability noted in what the care home means to residents with MS, and in particular, variability with regards to their acceptance of the care home as a place to reside in for their remaining natural life, suggest that it is important to understand the actual processes involved in adapting to the care home environment, so that better adaptation processes can be promoted. For some individuals, this adaptation process may have parallels with the concept of response shift [38], which involves changing internal standards, values and the conceptualisation of QoL in light of significant life changes; in this case, a move to the care home. One possible way in which response shift may occur, is through downward social comparison processes (ie comparing themselves favourably to those that are worse off), which was reported by a number of residents with MS. However, further investigations are needed to clarify how such processes may occur.

It has been suggested that a perspective focusing on both the individual (e.g. attitudes to the care home) and environment (e.g. physical environment of the care home) is necessary to facilitate good QoL in the care home [29]. The four components of QoL identified in this study may also interrelate. Thus for residents with MS, MS-related issues such as limited mobility, pain, fatigue, and speech problems, may interact with environmental factors to impact on their QoL. This in line with the idea that environmental factors interact with a health condition to create a

disability or restore functioning, depending on whether it is a facilitator or barrier [39]. For example, a resident with MS experiencing pain and limited mobility living in a care home that do not provide opportunities to interact with residents or offer stimulating activities, may experience more social isolation and poorer QoL. It has been suggested that QoL in care home residents may not be “fundamentally different” from QoL of non-residents [19; 21], but that the residents’ experiences and living contexts may need to be taken account of when studying their QoL in the care homes [21]. This study has demonstrated that in the case of residents with MS, their personal factors, and in particular, their attitude towards the care home, will also have an impact on their QoL. Thus, in the same way that impairments are not linearly related to participation [11], or that disability status is not linearly related to QoL in people with MS [40], the interrelationships between impairment, personal and environmental factors and their contributions to QoL in the care home is complex, and requires further investigations to aid theoretical developments in this area. In some populations, such as community-dwelling older adults, QoL is a significant predictor of mortality, physical dependence and service utilisation [41]. Thus residents with MS in care homes and their relatives need to have confidence that their QoL is valued. Our study adds to a growing body of literature that suggests that addressing the QoL needs of residents goes beyond focusing on their physical health, and that a more holistic approach needs to be taken to address their QoL needs [42].

Understanding the components of QoL of residents with MS in care homes, can also aid in making practical and specific recommendations on what service providers can do to improve QoL. At a practical level, the components of the category of

Environment can be addressed by the care providers at both an organisational and individual care level [26]. The results from this study suggests that care providers may consider the following: more involvement of family members, fostering relationships amongst residents where possible, encouraging independence, by providing access to rehabilitation, especially physiotherapy, for residents, providing meaningful activities, staff training on MS-related issues, and identifying appropriate planning and support in the transition process, including psychological interventions either individually or with family members. The latter may be particularly important as some residents reported feeling abandoned by their family members. Care home living is a non-normative experience for younger people, and care homes are typically designed for older adults [42]. This makes it especially crucial to identify practical ways in which residents with MS, who are often younger and whose family members often live in the community, can experience better QoL. More recently, the lack of coherent arguments relating to the complexities surrounding young people in care homes, and especially the lack of evidence-based research in this area has been highlighted [43]. It is clear that a more thorough understanding of the decisions faced by younger people who are faced with living in care homes is needed.

A limitation of the study is that the care home managers identified the participants. Not all identified residents were interviewed, due to cognitive or speech difficulties. Thus the sample may not be representative. As the interviews were conducted in the care homes, responses may have been biased towards more positive attitudes. Although this study identified significant issues, they cannot be used to make statistical generalisations. The purpose of qualitative research is to provide an in-depth description and interpretation of the phenomena being studied [44]. This

qualitative study could not equivocally determine whether residents with MS living in care homes specifically catered for young people, or those with good Care Quality Commission scores, have better QoL than those living in other types of homes. Nor could it determine whether those residents who have been in the care home for longer have better QoL or report better adaptation. These are avenues for further research, possibly using more quantitative methods.

Services and policy decisions need to reflect the views of care home residents with disabilities. Some practical recommendations have been suggested based on this study on the perspectives of residents with MS. Furthermore, a broad assessment of residents' QoL is necessary. A measurement tool based on this study, for use in research, audit and treatment evaluations, is now in development.

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Declaration of interests

The authors report no declarations of interests.

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