


Received 19 October 2010; accepted in revised form 28 March 2011

Assessing quality-of-life in older people in care homes

SUE HALL1, DIANA OPIO2, RACHAEL H. DODD1, IRENE J. HIGGINSON1

1King’s College London, Palliative Care, Policy and Rehabilitation, London, UK
2Guy’s and St Thomas’ NHS Foundation Trust, Palliative Care, London, UK

Address correspondence to: S. Hall. Tel: +44 (0) 2078485578; Fax: +44 (0) 2078485517. Email: sue.hall@kcl.ac.uk

Abstract

Background: many measures of Quality-of-Life (QoL) may not be suitable for older people in care homes, and do not cover the most relevant domains for individuals.

Objective: to describe QoL of older people living in care homes using the SEIQoL-DW and the two 10-point rating scales, and to describe how people were using these measures.

Design: we used quantitative methods to describe QoL, and qualitative methods to explore residents’ experiences of completing the measures.

Setting: three care homes in the United Kingdom.

Sample: twenty residents.

Methods: residents completed the measures in interviews. We report descriptive statistics for QoL, the most important QoL domains for residents, completion rates and experiences of administering the instruments.

Results: the most important QoL domains identified in the SEIQoL-DW were leisure activities; family; relationships; social life; independence and peace and contentment. Physical limitations and difficulty in understanding the instructions and concepts made completing it a challenge. The SEIQoL index was strongly correlated with a single 10-point rating of current QoL. \( \rho_{10} = 0.67, P = 0.007 \).
Conclusions: to fully understand residents’ QoL, detailed interview-based instruments, administered by an experienced interviewer are needed. To measure current QoL, for example, as an outcome measure, a simple single rating scale may suffice.

Keywords: quality-of-life, care homes, qualitative, SEIQoL DW, elderly

Introduction

In many countries, older people are increasingly cared for in care homes towards the end-of-life. Quality-of-life (QoL) is one area of assessment which might help those involved in the care of older people in these settings understand the needs of residents. Valid measures of QoL are also needed to assess the impact of interventions to improve the care of residents. However, the QoL of care home residents is relatively unexplored.

QoL is difficult to define because it is a subjective dynamic concept, demonstrated in the range of instruments, containing different dimensions, which have been used to assess it. Many measures used to assess QoL are measures of health, functional status, social behaviour or psychological wellbeing, and some, such as the SF36 [1], are not suitable for people living in care homes. For example, respondents are asked about lifting or carrying groceries and walking relatively long distances, which, in institutions, may reflect opportunity rather than ability. Predetermined lists of questions in many existing measures are based on assumptions about the factors determining an individual’s QoL, often determined by health professionals [2]. They are, therefore, based on external value systems, which may not be relevant to individuals.

The SEIQoL has been developed for the evaluation of QoL from the individual’s perspective [3]. It allows people to nominate the areas of life they feel are most important to them, rate their functioning on each and indicate the relative importance of each. The SEIQoL-DW is an abbreviated form, using a simpler procedure for measuring the relative importance of life areas [4]. Details of administration are in Supplementary data available in Age and Ageing online, Appendix 1. Although the SEIQoL-DW has been shown to be practical to administer in busy clinical contexts, and suggested as an outcome measure in trials [4], practical and conceptual concerns have been raised [5], and the measure has been used with older populations with varying degrees of success [6–9]. For details of these studies please see Supplementary data available in Age and Ageing online, Appendix 3.

QoL has been assessed relatively simply, without defining the components of QoL. Graham and Longman [10] used a brief global QoL scale comprising two 10-point Likert scales, one asked patients to rate their current QoL, the other asked them to rate their satisfaction with their QoL. This measure has also been used in studies of palliative care patients [11–13] and care home residents [14].

In summary, little is known of the QoL of older people in care homes, or the best way to assess this. The aims of this study are: to describe self-reported QoL of older people living in care homes using the SEIQoL-DW and the two 10-point scales; and to describe any problems residents had when completing these measures.

Methods

Design

We used quantitative methods to describe residents’ QoL and qualitative methods to explore experiences of completing the measures.

Ethical approval

King’s College Hospital Research Ethics Committee (ref: 07/H0808/177).

Participants and setting

Twenty older people living in one of three care homes for older people in London. The exclusion criteria were being unable to speak English or provide informed consent; or being too ill to take part in a semi-structured interview. For characteristics of residents, please see table in Supplementary data available in Age and Ageing online, Appendix 3.

Procedure

Care home managers provided eligible residents with information about the study. Measures were completed in face-to-face interviews, conducted in private, with one of three experienced female interviewers. We used concurrent verbal probing techniques [15] to explore the basis of residents’ responses. Seventeen interviews were fully recorded and transcribed verbatim. Two interviews were not recorded at the request of the residents, and one was partly recorded due to equipment failure.

Measures

SEIQoL-DW

Details of procedures for administering SEIQoL-DW are in Supplementary data available in Age and Ageing online, Appendix 1. After each interview, interviewers completed
an interview record form, which included their perception of (i) resident’s understanding of the method, (ii) resident’s fatigue/boredom level and (iii) the overall validity of the information. We calculated the global SEIQoL index by multiplying the level of each cue by the weights and summing the products of these. The score can range from 0 (lowest) to 100 (highest QoL).

Ratings of perceived QoL and satisfaction with QoL

We asked (i) How would you rate your current QoL? (from 1:poor to 10:excellent) and (ii) How satisfied are you with your QoL? (from 1:not satisfied at all, to 10:very satisfied). Ratings of perceived QoL and satisfaction with QoL were completed before the SEIQoL-DW.

Other measures

We assessed cognitive impairment using the Blessed Orientation-Memory-Concentration Test [16]. A score above 10 is considered abnormal. We used two measures of participants’ health status: Karnofsky scores to assess performance status [17] and Barthel scores to assess ability to perform activities of daily living [18]. Resident’s age, sex and ethnic group were also recorded.

Analysis

We report completion rates; responses to the interview record form and median and inter-quartile ranges of the QoL measures. We used Spearman’s Rank Correlations to determine the associations between the QoL measures. To present grouped data, we categorised cue definitions using the broad categories in the prompt list and any new categories that emerged (Table 2). Two authors independently categorised the cue definitions. Any discrepancies were resolved by discussion. One author compared residents’ definitions of QoL when completing the two QoL rating scales with SEIQoL cues, checked for discrepancies in ratings made and justification for these and conducted content analysis to identify the content and context of residents’ difficulties in completing these measures. These were checked by a second author, with any discrepancies resolved by discussion. Where participants’ quotes are used to support the results, names have been changed to protect their anonymity.

Results

Completion of the two 10-point scales

All 20 residents rated their current QoL on a 10-point scale; however, three of these were confused by the ‘satisfaction’ question and were unable to complete the rating. There were not major inconsistencies between participants’ ratings and their justifications for their scores, however, deciding on a number seemed difficult for some, who preferred to use verbal descriptors such as ‘a little more than half way up’ (Anne), or ‘Well… it’s not too good… and it’s not too bad’ (Alfred). It sometimes took some effort for residents to decide on a number and some needed the help of the interviewer. For example, Diane initially rated 10 instead of one, but corrected this when questioned by the interviewer (sections of transcript demonstrating the challenges to assessing QoL are in Supplementary data available in Age and Ageing online, Appendix 4).

Completion of the SEIQoL-DW

Seventeen of the 20 participants completed the SEIQoL-DW; one was too ill to continue; one was very confused by the cue elicitation task and one was unable to understand the rating task. Seven of the 17 residents who completed the SEIQoL-DW had problems understanding what they were being asked to do, and three appeared bored or fatigued by it. Based on this, interviewers judged two SEIQoLs as definitely invalid, and four as uncertain. Both the SEIQoLs judged invalid were completed by residents in the normal range on the Blessed Orientation-Memory-Concentration Test.

Three residents commented on the length or complexity of the introduction to the measure, and one thought it was a question and did not know how to respond. Most residents spoke at length about important aspects of their lives; however, this sometimes made it difficult to keep them focussed on the task. Cue elicitation was often difficult, and some residents preferred to nominate individuals rather than broader areas. This step was recorded for 16 residents: seven provided five cues with little help; five provided five cues with help from the interviewer; and four could not provide five cues. Help involved clarifying a label for a cue from a sometimes lengthy description, suggesting cues indicated in residents’ anecdotes or providing the prompt list. For example, Anne (who was in the normal range on the Blessed Orientation-Memory-Concentration Test) could only provide one cue without help. She seemed to find it hard to think beyond her concerns about being in the home. When shown the prompt list, she nominated ‘relationships’ at the suggestion of the interviewer. She was, however, tired, breathless, depressed and confused by the list (Supplementary data available in Age and Ageing online, Appendix 4). The interviewer felt it inappropriate to try to elicit further cues.

Physical impairments made drawing bar charts difficult. Only one resident did this independently, the others indicated their levels against the scale and the interviewer drew the bars. Three residents found themselves in difficulties with their nominated cues: Alfred who nominated ‘friendship’, Laura who nominated ‘relationships’ and William who nominated ‘people’ (community, other residents and care home staff) pointed out that the levels varied for different friendships, relationships or people (Supplementary data are available in Age and Ageing online, Appendix 4). A further three
residents had problems understanding the task and indicating levels to the interviewer.

Physical impairments made adjusting the disk to weight the cues very difficult. Four residents did this with help. The interviewer manipulated the disk for other residents, who indicated weightings. In addition to manipulating the disk, 11 residents needed help from the interviewer to decide on the weightings. Peter, who had managed without help so far, now struggled with the weighting procedure (Supplementary data are available in Age and Ageing online, Appendix 4). He felt that four of his cues, depended on the fifth: freedom, so was unsure how to weight them. He arrived at a solution with the help of the interviewer, but became irritated by the task.

QoL scores
QoL scores were moderately high (Table 1). There was a strong association between rating of current QoL and satisfaction with QoL ($\rho = 0.82$, $P < 0.0001$). The single item rating of QoL was strongly associated with the global SEIQoL index ($\rho = 0.67$, $P = 0.007$), but not satisfaction with QoL ($\rho = 0.33$, $P < 0.215$).

SEIQoL quality-of-life domains
The 18 residents, who nominated cues produced 82: 14 nominated five; one nominated four; two nominated three and one nominated two. The categories and their cues are shown in Table 2. The most frequently nominated cues were leisure activities; family; relationships; social life; independence and peace and contentment. The latter two are not in the prompt list and seem to be an area of particular importance to older people in care homes.

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>Cues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leisure activities</td>
<td>13</td>
<td>Going to the pub, TV, DVDs, entertainment, travelling, making models, reading, listening to music</td>
</tr>
<tr>
<td>Family</td>
<td>11</td>
<td>Mother, brother, daughter, seeing family, close and happy family, communication with son, sons</td>
</tr>
<tr>
<td>Relationships</td>
<td>9</td>
<td>Relationships, friend(s), friendship (4), special friend, people (community, residents, staff), not being lonely</td>
</tr>
<tr>
<td>Independence</td>
<td>8</td>
<td>Freedom, independence, mobility, can do what they want to do, autonomy</td>
</tr>
<tr>
<td>Social life</td>
<td>6</td>
<td>Socialising, social life, social events, communication with others, visits from people, stimulating conversation</td>
</tr>
<tr>
<td>Peace and contentment</td>
<td>6</td>
<td>Peace of mind, inner peace/meditation and reflection, no worries, being happy, peace in the world</td>
</tr>
<tr>
<td>Health</td>
<td>5</td>
<td>Feeling good, good health, can speak again</td>
</tr>
<tr>
<td>Living conditions</td>
<td>5</td>
<td>Feeling secure in the home, warmth/comfort in room, feeling at home, caring environment, home</td>
</tr>
<tr>
<td>Religion/spiritual life</td>
<td>4</td>
<td>Expressing spirituality, religious rituals, church/fait, religion</td>
</tr>
<tr>
<td>Outside</td>
<td>4</td>
<td>Fresh air and nature, nature and watching squirrels, fresh air and going out for walk, going out of the home</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>Food (3), Work (2), housework, finances, smoking, pets, memories, welfare of other residents</td>
</tr>
</tbody>
</table>

Table 2. Cues nominated by residents

Discussion
Residents who were willing and able to take part in this study reported moderately high levels of QoL. Although many residents found the SEIQoL-DW a challenge to complete, it gave us insight into the domains that residents feel are important to their QoL. The most frequently nominated domains of QoL identified by the SEIQoL-DW (leisure activities; family; relationships; social life) have also been found to be important to older people in other settings [6–9]. For comparison of the domains reported in these, and the current study, please see Supplementary data available in Age and Ageing online, Appendix 5. Since much of their time in these homes is spent on organised social activities and leisure activities such as watching television, reading and listening to music, it is perhaps not surprising that these are important aspects of QoL. Family was less frequently nominated, possibly because residents often no longer had any close family. Since all the participants in our study had a range of medical problems, it is surprising that health was rarely nominated. This was nominated by at least half of the respondents in three other studies of older people [6, 8, 9] and nearly half in another [7]. This may reflect a response shift. As a result of chronic illness and disability, people often change their internal standards, values or conceptualisation of QoL [19] to help them adjust to the increasing limitations on their lives. High levels of disability, and living in an institution, can make
achieving the levels of independence that many people would take for granted, an important part of QoL. ‘Peace and contentment’ reflect psychological and spiritual well-being, which is often overlooked in care homes. Training care home staff to ask individuals about the most important aspects of their lives which contribute to their current QoL (using prompts if necessary) can help them to provide care that optimises QoL.

Physical impairments made it difficult to administer the SEIQoL-DW. Similar problems have been reported in other studies [5, 9]; however, the problems were highly prevalent in our study. Since most residents needed help to complete the instrument, the possibility that some residents may have acquiesced with the interviewer’s suggestions cannot be ruled out. The strong correlation between the global SEIQoL index and the 10-point rating of current QoL suggests that this was not often the case. There have been suggested adaptations to the SEIQoL-DW: the bar chart could be replaced by a more simple visual analogue scale [9]; and the disk replaced with 100 counters which respondents distribute across five vessels, each labelled with a cue [5].

All residents managed to rate their current QoL on a 10-point scale, and, since QoL is not defined, no external values or definitions are imposed on them. This raises the question of whether it is necessary to encourage participants to focus on specific domains. It has been suggested that the SEIQoL-DW assesses the determinants of QoL rather than QoL [5, 20]. The strong association between the SEIQoL index and the single rating of current QoL suggests that these are measuring the same construct, although this needs to be explored in a larger study.

To the best of our knowledge, this is the first study to administer the SEIQoL-DW to residents of care homes. The findings provide important insights into the factors which residents feel are important to their QoL. Audio-recording allowed a detailed exploration of administration of these measures which can inform on their feasibility, acceptability and validity. The main limitation is the small sample. In the United Kingdom, 67% of residents of nursing homes and 52% of those living in residential homes have a degree of dementia [21]. Although people with moderate cognitive impairment may be able to discuss their QoL with an experienced interviewer, we felt it inappropriate to ask them to complete the SEIQoL-DW. It is possible that residents with poor QoL declined to take part in the study. Such residents may have nominated different QoL domains.

Conclusions

To fully understand residents’ QoL, detailed interview-based instruments administered by an experienced interviewer are needed. However, since most people who move to care homes do so because of increasing frailty, many residents would experience the problems the SEIQoL-DW described in our study, even with the suggested adaptations. To measure current QoL, for example, as an outcome measure, a simple rating scale may suffice, however, the reliability and validity of this measure needs to be explored more fully.

Key points

- Increasing numbers of people will die in care homes, yet little is known of their QoL or how to assess it.
- Leisure activities, family, relationships, social life, independence, and peace and contentment were important for residents’ QoL.
- Physical limitations and difficulty in understanding the instructions and concepts made completing the SEIQoL-DW difficult.
- Detailed interview-based instruments are needed to understand residents’ QoL.
- A single rating scale may suffice to measure current QoL as an outcome measure.

Acknowledgement

We are grateful to the care home staff for their help, and to the residents who took part in this study.

Conflicts of interest

None declared.

Funding

This study was supported by a grant from the Dunhill Medical Trust.

Supplementary data

Supplementary data mentioned in the text is available to subscribers in Age and Ageing online.

References


Received 10 November 2010; accepted in revised form 18 February 2011