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How Well do Elderly People Complete Individualised Quality of Life Measures:

An Exploratory Study

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Running head: Individualised quality of life and older people

Abstract

This research note describes and discusses a study which investigated the feasibility of using an individualised approach to measure the quality of life (QoL) of a sample of older people who were in receipt of an early hospital discharge service. Most participants (86%) were able to identify areas of their lives which were important to them, rate their level of functioning on each of these areas and rank their life areas in order of importance. However, 39% were unable to quantify the relative importance of each area of life. Indeed, the majority (57%) of participants who were over 75 years old could not complete this "weighting" or evaluative stage. The results suggest that the phenomenological approach to measuring QoL may be employed successfully with older people but that the "weighting" system used by existing individualised QoL measures needs to be refined, especially when assessing people over 75.

Keywords

How Well do Elderly People Complete Individualised Quality of Life Measures: An Exploratory Study

Introduction

Whilst the continued extension of human life expectancy is to be welcomed there is a pressing need to focus – more than ever before – upon the quality of existence of older people. Quality of life (QoL) – and its measurement – takes on added importance in the context of efforts to evaluate service effectiveness and to allocate health and social care resources. QoL in older people has tended to be perceived as being synonymous with functional ability and consequently most evaluations have employed measurement tools such as the Index of Activities of Daily Living[1] or the Barthel Index.[2] Other instruments have used a multidimensional approach such as the Older Americans Resources and Services Instrument[3] and the Functional Assessment Inventory.[4] These instruments define quality of life in terms of social and economic resources and physical and mental health as well as functional status. The use of a range of instruments containing different dimensions and scales to measure QoL demonstrates that there is a lack of consensus about the definition and measurement of QoL for older people.

QoL is difficult to define because it is a subjective, dynamic concept[5] based on an individual's internal frame of reference or understanding and perceived life experience. Existing generic measures of quality of life used with older people do not take into account some areas of life identified as important by older people such as family relationships.[6] More fundamentally, generic and population-specific questionnaire measures of quality of life used with older people consist of pre-

determined items and domains which are pre-supposed to be equally important. Furthermore, the content and structure of the QoL measures tend to be developed from the "top-down" by clinicians and academics. Outcome assessment needs to incorporate the unique perspective of each older person on his or her own quality of life.[7] This phenomenological approach to the measurement of QoL has received increasing attention among health psychologists and health care researchers. Several measures of individual QoL have been developed. The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)[8] allows respondents to identify areas of life which are important to them, rate their level of satisfaction or functioning with each aspect and rate the relative importance of each area. The Patient Generated Index (PGI)[9] consists of three similar stages although a slightly different rating system is used. In addition, the PGI requires patients to state the five most important areas of life affected specifically by their medical condition. By framing the responses in this way, the PGI can be perceived as a measure of disease-specific health-related QoL. The Subjective Domains of Quality of Life Measure (SDQLM)[10] allows respondents to identify areas of importance in their life, to rate these areas on an individually generated continuum and also to indicate the rank importance of each area.

The SEIQoL has been used successfully (in so far as all respondents were able to complete every section) with a number of different population groups such as people with HIV/AIDS,[11] patients undergoing hip replacement[12] and patients with gastrointestinal disorders.[13] The PGI has been used successfully for patients with obstructive sleep apnoea,[14] people with atopic dermatitis[15] and people with back pain,[9] though only 63% of people with back pain were able to complete correctly a self-administered version of the PGI. The SDQLM has been tested on people with hypertension.[16] However, only the SEIQoL has been used in any published research

which involved a group of older people. Browne et al.[17] reported that 10% of healthy elderly community residents were unable to complete the final "weighting" stage of the SEIQoL and Coen et al.[18] found that 70% (14/20) of older people with mild dementia were either unwilling or unable to complete the full procedure. As a result of these and other findings, the authors of the SEIQoL have attempted to design a simpler method of weighting the domains of life identified in the SEIQoL,[19] though there is no published work which assesses the appropriateness of the use of this "direct weighting" method with older people. The authors of the present paper had an opportunity to investigate some of the issues surrounding the use of individualised measures of QoL in the context of undertaking an evaluation of early hospital discharge schemes for older people. We were interested in developing and adapting an individual measure of health-related QoL with older people which could be administered routinely in clinical practice and as an aid to service evaluation.

Method

The development of the QoL measure for use with older people.

The PGI was the QoL measure chosen because it focuses on health-related QoL, takes a shorter time to administer than the SEIQoL and there is a need to investigate its use with older people. Initial pilot interviews indicated that older people may have a problem with the completion of the weighting stage of the PGI in the same way as problems were identified with this stage of the SEIQoL. Therefore, an extra stage was added to the PGI, prior to the weighting stage. The additional stage required respondents to rank in order of importance the life areas they had identified.

This extra stage was derived from the SDQLM with the aim of assisting respondents to determine the relative importance of each life area. In addition, changes were made to the rating system used in the original PGI and together with the additional stage noted above this led to the development of the Modified Patient Generated Index (MPGI) which comprised the following stages. Stage 1 asked participants to identify up to five areas of their life which were important to them and had been affected by their illness or condition. Stage 2 allowed participants to score each of these areas from 0 to 100 to reflect how they rated themselves on each area at that moment - 0 indicated "the worst you could imagine" and 100 indicated "exactly as you would like to be". At stage 3, participants ranked each of the areas they had identified (at Stage 1), beginning with a score of 1 for the most important area of their life. Stage 4 asked participants to imagine they had been given £100 to spend in order to improve the areas of life they had already identified and then to determine how much money they would spend on each area.

Although the MPGI is an individual measure of health-related QoL, a total score for each individual can be calculated for group comparisons using the following formula which is based on the formula for calculating total scores on the PGI: Σ(Stage 2 * (Stage 4/100)). This results in a possible range of scores from 0 to 100, with a higher score indicating a higher quality of life. The same formula is used in the SEIQoL for calculating a total QoL score.

Procedure

The MPGI was administered in the form of a face-to-face interview to 36 older people (30 females, 6 males) between the ages of 66 and 95 years (mean (sd) = 78.4 (6.4) years) as part of a larger study evaluating an early hospital discharge

scheme. The MPGI had been administered to 23 (4 males) of these older people at an earlier point in time. Interviews took place when the patient was discharged from hospital and the repeat interview was conducted when they were discharged from the early discharge scheme. Interviews were 6 weeks apart, on average. The participants had been admitted to hospital diagnosed with a range of disorders requiring both medical and surgical treatment. The most common condition was a fracture or hip replacement.

Results

Stage 1 was considered to be complete if participants could nominate at least one area of life which was important to them. Stage 1 was completed by 31/36 participants (see Table 1). Five people could not complete Stage 1 and so were not asked to complete any other part of the MPGI. The 31 respondents who were able to complete Stage 1 had no difficulty in completing Stages 2 and 3.

Stage 1 asked clients to identify areas of their life or things which are important to them and have been affected by their condition. The most common responses were "mobility", "personal care" for example washing and dressing, "shopping" and "housework". The other life areas identified by respondents are summarised in Table 2.

Nine of the 31 respondents who completed stages 1, 2 and 3 were unable to complete Stage 4. There were no statistically significant associations between completion or non-completion of the MPGI and the sex ($\chi^2 = 0.19$, df = 1, p = 0.66) or medical condition ($\chi^2 = 2.67$, df = 4, p = 0.62) of participants. However, those who

were not able to complete the MPGI were significantly older than those who were able to complete the instrument ($t = 2.06$, $p = 0.04$). Investigation of the distribution of ages appeared to indicate that there were three separate bands: (a) participants aged between 66 and 75 years had little difficulty completing the MPGI; (b) participants aged between 76 and 80 years had approximately a 50% chance of being able to complete the MPGI; and (c) participants aged 81 years and over were most unlikely to complete the MPGI (see Table 3).

Total scores at both points in time could be calculated for only 12 participants, as completion of Stage 4 is essential for derivation of the total score formula given above. Analysis of these scores using the Wilcoxon Test showed a significant increase in respondents' overall quality of life ($z = 1.99$, $p = 0.02$, 1 tailed). The median total health-related QoL score at time 1 was 0 and 11/12 clients scored 20 or less. This indicates that almost all clients perceived themselves as having a very low quality of life at that time. The median total HRQoL score at time 2 was 25.

Discussion

The results tend to indicate that, overall, it is feasible, meaningful and worthwhile to use an individualised approach to measure HRQoL among older people, though further developmental work is required. Most people (72%) had little difficulty generating at least three areas of life which were important to them and could easily self-rate and rank order the importance of each area. The PGI and the SEIQoL allow, but do not require, a maximum of five areas to be identified and the SDQLM only asks for three domains of life which are important to the person. Of the

five older people who could not identify any life domains, two had a mild form of dementia and one was hearing impaired and could not understand what was being asked.

Everyone who completed stage 1 of the MPGI identified mobility as an important life area. This is to be expected as most participants in the study had been hospitalised due to fractures or for hip replacement. Indeed, the majority of life areas identified could be grouped under the physical mobility / activities of daily living heading. The respondents in this study placed little emphasis on social or emotional issues or on the area of family relationships which was found to be important among older people in a previous study.[6] This suggests that for this group, many of the pre-determined items in a general QoL questionnaire such as the SF-36 would have been redundant; yet if a measurement of ADL only had been administered, we would not have been confident of having assessed all areas relevant to the QoL of the participants. The individualised approach appears to represent a way of overcoming the difficulty of capturing individual variability.

The administration of the MPGI allowed the calculation of total scores which showed a significant increase in the HRQoL of the group - albeit a reduced number - between the two points in time. It is reassuring that as participants regained some mobility and increasingly became able to perform the activities of daily living, their HRQoL also improved. The MPGI was able to provide a reliable index of this significant change. However, the sample in this study indicated an apparently low HRQoL at both points in time relative to the possible range of total scores (0-100). Yet it may be that this range of scores is measured on an unequal interval scale with a bias toward the lower end of the scale. This would mean that the low median scores on the MPGI reported in this study and the low median scores on the PGI reported by

its authors[9] do not necessarily equate with low HRQoL. To interpret these scores accurately, more work is required to establish norms for comparative purposes as only Browne *et al.*[17] report total individualised QoL scores for healthy older people (mean = 80-82). However, these scores were calculated from the SEIQoL using the weighting procedure which has now been modified as it was found to be unfeasible with people who have mild cognitive impairment.

The main problem with the MPGI arose when respondents were asked to weight the relative importance of each area of their life. Many respondents had difficulty understanding or categorising areas in terms of relative importance. More specifically, it appeared that people aged 75 years and under had little problem with this concept whereas a significant proportion of participants over the age of 75 years and a larger proportion in the 80 years and over age range were unable to grasp this concept. However, these age cut-off points should only be taken as rough guidelines because although the overall sample size in the present study is comparable with previous work in the area,[11, 12, 13, 19] there are discrepancies between the numbers within each of the age groups. These groups were established *post hoc* in an attempt to explain the findings of the t-test reported in the results section which included the total sample. Further work with *a priori* decisions about the numbers in different age bands and an increased number of males is required to confirm these findings.

The present study serves as an indication of a potential problem with individualised measures such as the MPGI – the difficulty experienced by older people in the completion of a weighting stage. Further work is required to investigate why this problem exists. It may be the result of the negative correlation which has been shown to exist between cognitive function and age in older people,[20, 21] though this relationship was not tested in the present study. The results do show that all 31

patients who understood the nature of the MPGI and were able to complete stage 1 were also able to rank the areas of life they had identified in order of importance. Clearly, these participants were capable of evaluating one area of life against another but the method of converting a rank into a relative score was problematic. This suggests that it is the methodology of stage 4 of the MPGI which is not a suitable method for generating and then assigning weights to different life areas for older people. The SEIQoL now uses a visual aid to assist the assignment of weights and there is some evidence to indicate that aids of this kind are acceptable to respondents and produce reliable results,[19] though this procedure has not been tested with older people. Further work is required to identify a weighting system which is appropriate for use with older people particularly the very old and people with cognitive impairment.

In order to design an appropriate weighting system for older people, researchers need to know why the methodology of the MPGI is problematic. Perhaps this question could be addressed using a qualitative study which would allow older people to indicate why they have difficulty with certain methodologies. Meanwhile, immediate solutions to the problem are worth considering. One solution may be to ignore the weighting system and rely on the ranking system (Stage 3 of the MPGI). This would allow the order of importance of the life areas identified by a respondent to be determined but would not allow the calculation of a total HRQoL score for that respondent using the equation for the PGI or SEIQoL. Perhaps in cases such as these the rating for the most important area of life (as indicated by the respondent) could be an index of the respondent's HRQoL. In the present study, the change in MPGI total scores were correlated with the change in the self-rating for the most important area of life indicated by respondents. The correlation was moderate using Spearman's rho

(rho = 0.6, p = 0.03), though this was achieved with a small number of respondents (n = 12). Alternatively, the weighting procedure could be omitted and total scores could be obtained by summing Stage 2 scores and dividing by the number of areas identified by the respondent. This would give a total HRQoL score which ranged from 0 to 100 but would be unweighted, much like commonly used QoL questionnaires with pre-determined items.

Another potential solution might involve the use of a visual aid to assist older people to assign weights to the various domains. The visual aid used as part of the SEIQoL is a stack of five centrally mounted, interlocking, laminated discs. Each disc is a different colour and is labelled with one of the five life areas nominated by the individual. "The discs can be rotated over each other to produce a dynamic pie chart where the relative size of each sector represents the weight the respondent attaches to a QoL domain. The proportion of the chart that each sector represents can be scored from a 100-point scale on the circumference".[19] This procedure could be awkward for an older person to use because it requires fine motor skills to manipulate the disc and the relative proportions of the pie chart attributed to each domain will depend upon the person's visuo-spatial ability. Currently, the authors are investigating various ways in which older people can be assisted to weight areas of importance. For example, the nominated areas of life are written in large letters into five "boxes" which fill one side of an A4 page. Each respondent is then given 20 tokens and asked to allocate or place the tokens on top of each box. The importance of a domain or box to each older person is indicated by the number of tokens placed on each box. This would negate the need to rank each item (Stage 3 of the MPGI) and would allow the calculation of a total HRQoL score using the formula Σ(Rating of domain * (Number of tokens placed in that domain/20)).

In conclusion, it is important to note that this study is limited in terms of its small sample size and that there is a need for further research into the issues surrounding the use of the individualised approach to measuring health-related QoL with older people. Normative data are required in order to assist the interpretation of total scores derived from existing individualised measures such as the SEIQoL or the PGI; and the weighting system used by present individualised measures appears to be inappropriate for use with people over 75 years of age. Finally, developmental research should investigate and describe, using qualitative methods, the features of the phenomenological experience of older people including, for example, the nature and extent to which individuals vary in the way they undertake a comparative evaluation of life domains. This should be complemented by a prospective, longitudinal study designed to investigate the way in which variables such as age, sex and home environment affects the validity of the individualised approach to quality of life measurement.

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Table 1: Number of life areas identified by respondents (n=36)

Number of areas identified at Stage 1 of the MPGI	Frequency
1	31 (86%)
2	30 (83%)
3	26 (72%)
4	13 (36%)
5 (maximum)	7 (19%)

Table 2: Areas of life identified and their relative importance as perceived by

respondents (n=31)

Area of life identified	Most Important				Least Important	Totals
Mobility	11	9	8	3	0	31
Personal care	4	4	6	3	3	20
Shopping	3	3	3	3	0	12
Housework	3	5	2	1	0	11
Hobbies/pastimes	0	2	4	0	4	10
Driving	2	3	1	2	0	8
Religion	2	3	0	0	0	5
Self-confidence	3	0	1	0	0	4
Family	2	0	0	0	0	2
Being free from pain	1	1	0	0	0	2
Working	0	0	1	1	0	2

Table 3: Age and numbers of participants who completed each stage of the MPGI

Age Range (years)	Total Number male:female	Number who were able to complete Stages 1, 2 and 3 male:female	Number who were able to complete Stages 1, 2, 3 and 4 male:female
66-70	3	3 (100%)	3 (100%)
	0:3	0:3	0:3
71-75	10	10 (100%)	9 (90%)
	2:8	2:8	2:7
76-80	13	10 (77%)	6 (46%)
	3:10	3:7	2:4
81-85	5	5 (100%)	2 (40%)
	0:5	0:5	0:2
86-95	5	3 (60%)	2 (40%)
	1:4	1:2	0:2
Totals	**36**	**31 (86%)**	**22 (61%)**
	6:30	**6:25**	**4:18**