Assessing quality of life in cardiac rehabilitation: Choosing an appropriate tool


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Assessing Quality of Life in Cardiac Rehabilitation – A Review of Measurement Instruments

Martin Dempster
Queen’s University Belfast

Health Psychologist
School of Psychology
Queen’s University Belfast
University Road
Belfast BT7 1NN

Tel: 028 90975547
m.dempster@qub.ac.uk
Abstract

Quality of life is an important outcome for people undergoing cardiac rehabilitation. This paper discusses the difficulties with defining the concept of quality of life and how it might be distinct from the concept of health-related quality of life. Based on a review of the literature, a description is provided of health-related quality of life questionnaires that have been used among cardiac rehabilitation populations. Some criteria for choosing between these questionnaires are then discussed and, finally, a brief discussion is presented of the concept of response shift and how this might influence the assessment of health-related quality of life in a cardiac rehabilitation setting.

Keywords:
Quality of life, cardiac rehabilitation, questionnaires, review
Quality of life is an important outcome in many clinical trials and often the improvement of quality of life is a stated goal of cardiac rehabilitation programmes. But what do we mean when we refer to “quality of life”? This review aims to encourage a debate among clinicians and researchers about how quality of life is defined and, consequently, how this informs the way it is assessed in practice.

Defining Quality of Life

The only thing certain about psychosocial phenomena is that they are riddled with complexity and uncertainty. That is not to say that we do not understand psychosocial phenomena, rather that as our understanding of these phenomena develops, so does our realisation about their complexity. Our innate desire to reduce complexity to simplicity must be overcome when dealing with psychosocial issues if we are to truly understand and, therefore, work in a meaningful way with these issues. Consequently, there is no simple definition of quality of life. One only needs to take a cursory look at the content of instruments that purport to measure quality of life to discover the differences that exist between the authors of these instruments in how they have operationally defined quality of life. Therefore, there is an onus on any clinician or researcher using quality of life as an outcome measure to delineate their operational definition of this term and how this led to the measurement instrument of choice.

Quality of Life Assessment in Cardiac Rehabilitation
What follows is a summary of a rapid review of quality of life instruments used in research involving people attending any phase of a cardiac rehabilitation programme. Three electronic databases were searched for any research articles that included the keywords ‘quality of life’ and ‘cardiac rehabilitation’. The electronic databases were PsychInfo, which includes psychology and psychology-related journals; Medline, which includes medical and related journals; and the Cumulative Index of Nursing and Allied Health Literature (CINAHL), which includes journals aimed at nurses and allied health professionals. The searches on each database were limited to articles which were published in peer reviewed journals, which were written in the English language and which were about humans. The number of articles returned by the search on PsychInfo, Medline and CINAHL was 59, 339 and 140, respectively. Once duplicates had been removed a total of 378 unique articles were retrieved. Of these 378 articles, a total of 230 were considered irrelevant, primarily because they were reviews, commentaries or discussion papers about cardiac rehabilitation; or they did not include a sample of people who had attended or were attending cardiac rehabilitation; or they did not include a measure of quality of life. For the purposes of this review, a measure of quality of life was considered to be an instrument which purported to assess quality of life or health-related quality of life and which provided quantitative data. Therefore, instruments which were designed to assess a specific aspect of quality of life only (eg. mood) were excluded from this review.

In the 148 research articles remaining in the review, 26 unique instruments were used to assess quality of life. The following questionnaires were used in only one
study each to assess quality of life: the Cardiac Assessment Instrument (Mithal et al, 2007), the Cardiac Health Profile (Wahrborg and Emanuelsson, 1996), the Chronic Heart Failure Questionnaire (Guyatt et al, 1989), the Duke Health Profile (Parkerson et al, 1990), the Psychological General Well Being Scale (Dupuy, 1984), the Goteburg Quality of Life Instrument (Tibblin et al., 1993), the Hacettepe Quality of Life Questionnaire (Oto et al, 1991), the Karolinska Questionnaire (Linde, 1996), the Leiden Quality of Life Questionnaire (van Elderen et al, 2000), the Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (Browne et al, 1997), the Utility-based Quality of Life – Heart (Martin et al, 1998), the Quality of Life Assessment Package (Woodend et al, 1998), the Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott et al, 1993), and the Dartmouth COOP charts (Nelson et al, 1990).

Quality of life questionnaires used in more than one study are listed in Table 1. Information about these questionnaires and where they can be accessed is provided in Table 2. It is clear from Table 1 that the SF-36 and the MacNew are the most commonly used quality of life assessment instruments in research among cardiac rehabilitation populations. Nevertheless, a considerable range of choices faces the researcher or clinician who wishes to assess the quality of life of cardiac rehabilitation participants. The following sections of this paper aim to guide the researcher or clinician to an appropriate choice of instrument, based on a number of decisions.

Health-Related Quality of Life
Perhaps the starting point for considering our definition, and method of assessing quality of life is to decide whether we want to measure quality of life or health-related quality of life. For those who work in a health care setting, the choice is probably straightforward.

A person’s quality of life is likely to be affected by many things which are outside the control or influence of health professionals, for example, relationships at work and at home, job satisfaction, the number of holidays taken, and so on. Although the state of someone’s health might impact on these areas of life, there will also be other causal influences which are potentially more important than health. Therefore, it might be more reasonable to examine the ways in which health professionals can affect the health-related quality of life of an individual. Health-related quality of life is a term used to indicate that we are limiting our consideration of the quality of a person’s life to those areas that are most likely to be affected by their health. For many authors, the core components of health-related quality of life are social, emotional (psychological) and physical functioning, although this definition will differ depending on the choices made in response to the dilemmas presented in the remainder of this paper. My focus for the remainder of this discussion will be on health-related quality of life (HRQoL).

Choosing a HRQoL Questionnaire
When choosing a HRQoL instrument for use among a cardiac rehabilitation population, the following issues need to be considered.

Reliability, Validity and Sensitivity

Probably most important of all is to ensure that a chosen HRQoL instrument has evidence for reliability and validity. Without evidence to support these properties then we cannot be sure about what the HRQoL questionnaire is actually assessing.

The reliability of a HRQoL questionnaire refers to its stability. This can mean stability over time (the extent to which you would obtain similar results in repeated administration of the test), which is usually indexed by a test-retest reliability coefficient, or internal stability (the extent to which the items within the instrument are related to each other), which is usually indexed by Cronbach’s alpha. In either case, the value of the reliability statistic ranges from 0 to 1, with values closer to 1 indicating higher reliability.

When an instrument is valid, it means that it measures what it claims to measure. Validity is population-specific. That is, just because there is evidence for the validity of an instrument in one population, it does not follow that the instrument is likely to be valid in other populations. Therefore, before choosing a HRQoL questionnaire for use among people in cardiac rehabilitation, there should be evidence for the validity of this questionnaire when used among people attending cardiac rehabilitation or, at least, among people with heart disease. There are different types of validity for which
evidence can be provided. Probably the most convincing type of evidence for validity concerning a HRQoL questionnaire is evidence for construct validity.

Construct validity can be considered to take 3 different types: convergent validity, divergent validity and structural validity. Convergent validity is demonstrated when the HRQoL questionnaire relates to similar theoretical constructs in the way that it should. For example, a HRQoL questionnaire would be expected to discriminate (to some extent) between people with a diagnosis of depression and those without a diagnosis of depression. However, you would also want to show that your instrument did not correlate very strongly with a measure of depression otherwise it might lead you to wonder whether your instrument was actually measuring depression only rather than HRQoL. Evidence which demonstrates that your instrument is distinct from measures of other constructs is referred to as divergent validity.

Structural validity refers to the validity of the proposed structure of the HRQoL questionnaire. For example, many questionnaires are divided into subscales and the questionnaire information will tell you which items constitute the different subscales. An assessment of structural validity is an assessment of whether the questionnaire should be divided into subscales (that is, whether the subscales are sufficiently distinct) and whether there is evidence to support the proposed allocation of items to subscales. Evidence for structural validity is usually provided in the form of a factor analysis.

The sensitivity (or responsiveness) of a HRQoL questionnaire is an important property to consider when you intend to use the instrument to assess change. For
example, if you are proposing to evaluate a cardiac rehabilitation programme you will wish to assess HRQoL before and after the programme. However, if the questionnaire you use to measure HRQoL is not sensitive to change, then it might not be able to reveal the important changes that have resulted from the programme. Sensitivity of an instrument is usually demonstrated by an effect size statistic. The common effect sizes provided take the form of the change in mean scores on the instrument divided by a standard deviation. Values up to 0.5 are considered small; values between 0.5 and 0.8 are considered moderate; and values greater than 0.8 are considered large (McDowell, 2006, p.38).

**Generic or Condition-Specific Measure?**

The HRQoL questionnaires listed in Table 1 generally fall into two categories: generic questionnaires or condition-specific questionnaires. Generic questionnaires are questionnaires that have been developed to assess the HRQoL of people across a range of different conditions. Such questionnaires are valuable as they allow comparisons of the HRQoL of different groups, which can be taken into consideration in the allocation of resources.

A condition-specific instrument is an instrument that has been developed with a specific population in mind. For example, the MacNew questionnaire was developed specifically for people with heart disease (initially specifically for people who had experienced myocardial infarction). The value of this type of questionnaire is that the items are more likely to address specific issues of concern to this particular
population (e.g. frequency or severity of chest pain), thereby making the condition-specific instrument more sensitive to change.

Often, it is useful to include both types of HRQoL assessment in order to benefit from the strengths of both approaches.

**Individualised or Pre-Determined Measure?**

Most of the HRQoL questionnaires mentioned in Table 1 are pre-determined measures. That is, they take the form of a standard questionnaire where items are listed and the patient is asked to respond to each item using a set response scale, such as a simple yes or no answer or a Likert-type response scale ranging from strongly agree to strongly disagree. The items on these questionnaires have been pre-determined. In other words, the wording of each item has (usually) been carefully developed and the items have (hopefully) been tested for acceptability to potential respondents. The method of scoring each item and combining these scores will also have been tested. This results in a questionnaire which is presented in a standard format every time it is used.

The process outlined in the previous paragraph has been used in the development of questionnaires for many years and is an accepted approach which allows us to make direct comparisons between scores on the same questionnaire obtained at different points in time or by different respondents. However, this process is based on the notion that the phenomenon which is to be assessed by the questionnaire is one for which we have a clear definition, i.e. we know what we want to assess. As already
highlighted at the beginning of this paper, HRQoL is a difficult phenomenon to define and it can mean different things to different people. The individualised approach to HRQoL assessment embraces this complexity.

An individualised approach to HRQoL assessment allows the respondent to influence either the content of the items which they are asked to respond to or the means by which their responses are scored. The Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW) is a quality of life instrument which has been used among cardiac rehabilitation participants. This is an individualised approach which allows each individual to influence the content of items and the method of scoring. Respondents are asked to: 1) name the five most important domains in their life; 2) rate their functioning on each domain; and 3) indicate the relative weighting/importance of each domain. An overall score is then obtained by multiplying each rating (the result of step 2) by each weight (the result of step 3) and then summing these products.

The benefit of the individualised approach is that the operational definition of HRQoL is specific to each individual. Furthermore, the results of this approach provide more information than a simple numerical score. However, the individualised approach is more time consuming than administering pre-determined questionnaires and usually requires an interview setting. Furthermore, the process of applying a relative weight to each area of life is cognitively complex and can prove difficult for people with cognitive decline (Dempster and Donnelly, 2000). Therefore, some ‘partially individualised’ approaches have been more popular. For example, the Quality of Life Index – Cardiac Version asks participants to rate pre-determined items but then
allows respondents to rate the importance of each item, thereby allowing some degree of individualisation of the scores obtained.

**Response Shift**

Research has shown that the effectiveness of cardiac rehabilitation in improving HRQoL is potentially underestimated due to response shift (Dempster et al, 2010). Response shift occurs when an individual reports their HRQoL at two (or more) points in time but does not use the same frame of reference each time. That is, the expectations about their HRQoL and the comparators against which they assess their HRQoL can change. This means that a direct comparison of the measurements of HRQoL across time will result in the true change in HRQoL being either under or over estimated. Consequently, response shift can have a considerable effect on the effect sizes calculated from change in HRQoL scores and, as a result, can influence decision making about the effectiveness of cardiac rehabilitation.

Response shift occurs because of recalibration, reprioritization and reconceptualization (Schwartz and Sprangers, 2000). Recalibration is a change in one’s internal standards of measurement. For example, one’s initial idea of poor functioning might become anchored at a lower level over time due to downward social comparison. Reprioritization is described as a change in importance attributed to HRQoL domains, for example, your ability to function highly in your occupation may become less important to you over time. Reconceptualization is described as a change in the meaning of the HRQoL domains, in other words the domains
themselves may change. Thus, if an individual undergoes a change in any of these elements, the answers to the same items in a HRQoL assessment by the same individual may not be comparable over time, as originally thought. Consequently, the emergence of response shift may threaten the validity of the assumptions of HRQoL measurement and the tools used. Incorporating the response shift construct into HRQoL measurement may enhance our understanding of how people undertaking cardiac rehabilitation perceive their HRQoL over time and lead researchers and clinicians to enhance the methods of assessing change in HRQoL.

Response shift is often assessed using a ‘then-test’. For example, imagine HRQoL is being assessed at the beginning (pre-test) and the end (post-test) of a cardiac rehabilitation programme. At the end of the programme, participants are also asked to complete the then-test. The then-test asks respondents to complete the HRQoL questionnaire with respect to how they were at the pretest stage, i.e. the respondents are being asked to think back to how they were at the beginning of the cardiac rehabilitation programme and record their quality of life then, but from their present viewpoint. By taking the post-test and then-test in close proximity it is assumed that the measures will be completed with respect to the same frame of reference. Consequently, comparison of the post-test and then-test scores should provide a non-confounded indication of the actual change in HRQoL. The comparison of the mean pretest and then-test scores will reflect an estimate of the magnitude and direction of response shift effects.

When assessing response shift, there is an advantage to using individualised measures over predetermined measures in that the nature of response shift can be
more easily assessed. Changes in the domains selected by respondents as being most important to their HRQoL would reflect reconceptualization; changes in weights would reflect reprioritization; and changes in ratings would reflect recalibration (Ring et al, 2005).

**Conclusion**

In summary, the choice of a questionnaire with which to assess the HRQoL of people undertaking cardiac rehabilitation is not a simple decision. It is important to consider your conceptualisation of HRQoL, i.e. what do you mean when you use this term. This will help you decide which questionnaires are appropriate for your purpose (by matching your conceptualisation with the content of the questionnaires, including whether you feel that an individualised approach is most appropriate). It is also useful to choose both a generic and a condition-specific questionnaire. However, this will probably still leave you with a number of questionnaires to choose from. The choice should then be based on the questionnaire with the strongest evidence for reliability, validity and (where appropriate) sensitivity.
References


Ware JE, Kosinski M, Keller SD (1998) SF-12: How to Score the SF-12 Physical and Mental Health Summary Scales 3rd ed. QualityMetric Incorporated, Lincoln, RI.

Ware JE, Snow KK, Kosinski MK, Gandek B (1993) SF-36 Health Survey Manual and Interpretation Guide. The Health Institute, New England Medical Center, Boston MA.

Table 1: Frequency of Questionnaires Used to Assess Quality of Life

<table>
<thead>
<tr>
<th>Quality of Life Instrument</th>
<th>No. of Studies as Sole QoL Instrument</th>
<th>No. of studies used in conjunction with another instrument</th>
<th>Total no. of studies in which this instrument was used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Form 36 (SF-36)</td>
<td>72</td>
<td>11</td>
<td>78</td>
</tr>
<tr>
<td>MacNew Quality of Life after Myocardial Infarction Questionnaire</td>
<td>18</td>
<td>8</td>
<td>22</td>
</tr>
<tr>
<td>Quality of Life Index – Cardiac Version (QLI-Cardiac)</td>
<td>8</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>EuroQol 5-D</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Living with Heart Failure Questionnaire (LWHF)</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Short Form 12 (SF-12)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sickness Impact Profile (SIP)</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Nottingham Health Profile (NHP)</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Perceived Quality of Life Scale (PQOLS)</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cantril’s Self Anchoring Ladder</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>McMaster Health Inventory Questionnaire (MHIQ)</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>
**Table 2: Questionnaires Most Commonly Used to Assess Quality of Life in Cardiac Rehabilitation**

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Citation</th>
<th>Further Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>36 items measuring 8 dimensions: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/vitality, pain and general health perception.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Generic questionnaire / pre-determined</td>
</tr>
<tr>
<td></td>
<td></td>
<td>27 items measuring 3 domains: emotional, physical, and social.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Condition-specific questionnaire / pre-determined</td>
</tr>
<tr>
<td>QLI - Cardiac</td>
<td>Ferrans and Powers (1985)</td>
<td><a href="http://www.uic.edu/orgs/qli/questionnaires/questionnaireemain.htm">http://www.uic.edu/orgs/qli/questionnaires/questionnaireemain.htm</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Version IV has 70 items – 35 items measure the satisfaction of respondents with various areas of life and 35 items measure the importance of these life areas to the respondent. Items are separated into a</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Author</td>
<td>Description</td>
</tr>
<tr>
<td>---------------</td>
<td>--------</td>
<td>-------------</td>
</tr>
<tr>
<td>EuroQol 5-D</td>
<td>Euroqol Group (1990)</td>
<td>5 items assessing mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. There is also a general health rating scale presented as a thermometer. Condition-specific questionnaire / partially individualised</td>
</tr>
<tr>
<td>SF-12</td>
<td>Ware et al (1998)</td>
<td>12 items measuring 2 dimensions: physical health and mental health.</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Description</td>
<td>URL</td>
</tr>
<tr>
<td>---------------</td>
<td>-------------</td>
<td>-----</td>
</tr>
<tr>
<td>SIP</td>
<td>Bergner et al (1976)</td>
<td><a href="http://www.mapi-trust.org/services/questionnairelicensing/cataloguequestionnaires/118-sip">http://www.mapi-trust.org/services/questionnairelicensing/cataloguequestionnaires/118-sip</a></td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Details</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Cantril’s Self Anchoring Ladder</strong></td>
<td>A ladder with steps numbered 0 to 10. The respondent is asked to describe the best possible life quality s/he can imagine for the top of the ladder, and the worst possible life quality imaginable for the zero point on the ladder. The person then rates their life quality in relation to these extremes.</td>
<td></td>
</tr>
<tr>
<td><strong>MHIQ</strong></td>
<td>59 items measuring 3 domains: physical, emotional and social health.</td>
<td></td>
</tr>
</tbody>
</table>

**Generic questionnaire / individualised**