



Review

Quality-of-life measurement in chronic heart failure: do we take account of the patient perspective?

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Abstract

The modern management of chronic heart failure has led to improved life expectancy, functioning and health-related quality of life (HRQL). HRQL measures the effects of an illness or a treatment from the patient's perspective. It is now recognised that the patient's perspective is as legitimate and valid as the clinician's in monitoring health care outcomes. Although there are a number of quality-of-life measures, which can be separated into two types—generic and disease specific—many have been developed, with little or no account being taken of the patient's perspective. Because most of the widely used measures are not patient centred, they may lack sensitivity and specificity in determining those aspects of HRQL important to individual patients.

This paper reviews the use of quality-of-life assessment tools in the evaluation of patients with heart failure.

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Keywords: Health-related quality of life; Chronic heart failure; Patient centred

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1. Introduction

Coronary heart disease (CHD) is a major contributor to morbidity and mortality in Western societies [1]. Both the longevity of the population and advances in treatment have led to an increase in the prevalence of CHD in the population in developing countries [2]. Major advances in terms of prevention, treatment and rehabilitation have improved prognosis. As a result of these interventions, there is a population which is both older and more susceptible to morbidity due to advanced CHD. Modern management has led to improved survival, which is leaving more patients with a significantly damaged heart that is likely to fail at some time in the future [2].

2. Outcome of chronic heart failure

The diagnosis of heart failure has a comparable mortality rate to that of a diagnosis of cancer. Comparison with the West Midlands Regional Cancer Registry showed that 1-year survival rates for patients diagnosed with heart failure are worse than the 1-year survival rates for those diagnosed with breast, prostate and bladder cancer [3]. These findings support those of Stewart et al. [4] who studied the prognostic impact of heart failure relative to that of ‘high-profile’ disease states, such as cancer. They identified all patients with a first admission to any hospital in Scotland during 1991 for heart failure, myocardial infarction or the four most common types of cancer specific to men and women. Five-year survival rates and associated loss of expected life-years were compared. Their data showed that patients admitted to hospital with a diagnosis of cancer often survived longer than those with a diagnosis of heart failure. They concluded that, with the notable exception of lung cancer, which is worse, heart failure is as ‘malignant’ as many common types of cancer and is associated with a comparable number of expected life-years lost [4]. Heart failure is associated with poor health-related quality of life (HRQL; [5]) and increasing dependency [6] and may result in prolonged and frequent hospital admissions [7,8].

3. Effect of chronic heart failure on quality of life

In recent years, medical care has become increasingly concerned with the management of chronic diseases. In these cases, the aim of a medical management plan is to optimise the patients’ quality of life. Over the past decade, there has been a growth in the use of quality-of-life measurements as an indicator of health outcome [9,10]. Chronic heart failure (CHF) is no exception to this, where the goal of treatment is not only to prolong life, but also to relieve symptoms and improve function. Improving quality of life is an important goal of medical therapy; it is increasingly being seen as an important outcome to be measured in clinical research [11]. The medical profession has been slow and, perhaps, reluctant to quantify such subjective, personal and human characteristics, preferring to rely on laboratory tests, objective measures or population statistics for information [11]. Quality of life reflects the way a person’s mental and physical well-being is evident in their everyday life [12]. HRQL measures the effects of an illness or a treatment from the patient’s perspective. Although health care professionals may be more interested in changes in objective physical measures, patients tend to be more interested in changes in symptoms, physical function and social roles [13]. These HRQL measures are particularly useful and important supplements to traditional physiological measures of health status because they describe or characterise what the patient has experienced as a result of health care [11].

The main clinical symptoms in CHF patients that limit activities of daily living and lead to exercise intolerance are dyspnoea, tiredness and fatigue. The fundamental issue to patients is how these symptoms hinder their life. Individuals with CHF experience impairment of physical and functional capacity, which imposes limitations on their life [6]. Quality of life in CHF may be impaired by physical symptoms, psychological problems, adverse treatment effects and social limitations [14]. These factors may lead to individuals withdrawing from activities and previous social contacts and losing their social relations and social support [15]. Rifts caused by family members struggling to meet illness-related demands and the inability of family and friends to cope with the deterioration of a close friend lead to withdrawal of contact with the CHF patient [15]. The increasing severity

of CHF leads to the individual being aware of their own mortality; this also leads to depression, sleep disturbances and anxiety [14]. Personal relationships, eating, sexual activity and the ability to work are all limited and are paralleled by an increasing dependence on others [14]. Quality of life is an opinion formed by a person's interpretation of their own health status in comparison with what they might hope to be able to achieve [14]. Reduction in quality of life is an inherent problem to the individual with chronic heart failure.

4. Health-related quality-of-life measures in chronic heart failure

Two approaches to measuring HRQL are available: generic and specific instruments [16]. Generic instruments measure a wide variety of patients and usually cover a wide range of HRQL domains, including, e.g., functional capacity, disability and distress. Specific instruments concentrate on particular areas of relevance to the patient group. The choice of which instrument to use is vital, because the content must be related to the nature of the medical condition being treated, as well as to the effect of the treatment under assessment [17]. Therefore, a questionnaire suitable for the assessment of hypertensive therapy may not be suitable for evaluating the impact of cardiac surgery [18]. Most of the research that refers to HRQL has led to the development of measures that describe health status, which is not the same as quality of life. Quality-of-life research does share a number of similar fields to health status research, but it should be concerned with the individual rather than the group. Researchers have tended to use the terms “quality of life”, “health status” and “health-related quality of life” interchangeably [19].

4.1. Generic measures

There are a number of generic measures available that measure quality of life. Examples are the Nottingham Health Profile (NHP; [20]), the Sickness Impact Profile (SIP; [21]) and the Medical Outcomes Study 36-item Short Form Health Survey (SF-36; [22]). These are applicable for a wide range of groups and cover a wide range of quality-of-life domains (Table 1).

4.1.1. Nottingham Health Profile (NHP)

The Nottingham Health Profile [20] is a measure of perceived distress relating to severe disabling diseases. Originally developed using public perceptions of health status to assess factors which predict the need for health care [23], it provides a description of how people feel during ill health. The main aim of the measure is that it should reflect the individual's rather than the professional's definition of health. The NHP is a short scale and, thus, can be self-administered and is suitable for use in postal questionnaires;

however, its short length means that it does not provide a comprehensive assessment. Extensive testing has found the NHP to be reliable and valid [24–27]. However, it has been used in a number of clinical trials in heart failure and produced variable results [28–31]. This may have been due to its lack of sensitivity to symptoms experienced by patients with CHF. It may also be caused by its inability to detect minor illness, and therefore, minor improvements over time are not detected [32]. The assessment of pain is important in the NHP. This symptom is uncommon in CHF, and therefore, the content validity in relation to CHF is reduced. More studies are required on the validity and use of this measure in CHF.

4.1.2. Sickness Impact Profile (SIP)

The Sickness Impact Profile [21] is a generic measure which is widely used in angina. This was developed as a measure of perceived health status for use across a wide range of health problems. Sickness is measured in its relation to behaviour. The emphasis is on the impact of sickness on daily activities rather than feelings. It can be administered by interview, self-administered and by postal questionnaire. High scores for validity and reliability have been shown [24,33–36]. However, it is lengthy, and this can be a disadvantage. When the SIP has been used in interventional trials in CHF, it has shown variable results in improvements of quality of life in the intervention groups [37,38]. This may be due to its lack of sensitivity to HRQL changes in patients with CHF. Results in one study suggest that the SIP does not discriminate adequately between different severities of CHF [39].

4.1.3. Medical outcomes study 36-item short form health survey (SF-36)

The SF-36 [22] was developed to gather information about the individuals' multidimensional health concepts and a measurement of the full range of health domains, including well-being and personal evaluations of health. It was developed for a health insurance study by the RAND corporation [22] and is the most widely and extensively used generic measure [24,40]. This is due to the fact that it is short and has been tested for reliability and validity and found to be reliable and valid across numerous population samples [24,40–45]. However, there are reports of ceiling and floor effects in its use in chronic diseases [46]. It has been found to be more sensitive to small degrees of impairment in quality of life compared with that of the NHP. However, the SF-36 proved to be too long for inclusion in some large-scale health measurement and monitoring studies [47].

The SF-36 is suitable for use in heart failure trials and it can and should be used in conjunction with disease-specific questionnaires [48]. However, the incidence and prevalence of heart failure in the elderly population is high [3,7,49–51], and when this is taken into account, the usefulness of the SF-36 is doubtful. A study of older adults found that there

Table 1
Properties of generic quality-of-life measures

Measure	Nottingham Health Profile [20]	Sickness Impact Profile [21]	The 36-item short form health survey (SF-36) [22]
Description	Measure of broad health status among patients with angina. Developed in UK based on lay perceptions of health status.	Measure of perceived health status that would provide a descriptive profile of changes in a persons' behaviour due to sickness. Developed in the United States.	Measure of function and well-being. Used in a wide variety of circumstances.
Acceptability and appropriateness	Short, simple, inexpensive, self-administered, postal administered. Designed for use as a population survey.	Does not provide comprehensive assessment. High nonreturn rate if high number of zero scores focuses on negative experience. Does not detect minor illness and minor improvements over time not detected [32]. Large numbers of relatively fit members of the population survey would gain low NHP scores.	Self-administered, postal and interview administered. Wide application used in chronic and acute illness. Adapted for UK population
Validity	Established in the development method where items were drawn from lay experience. Numerous applications in clinical and community settings. Successful outcome measure with heart transplant patients in UK [25,26]	Lengthy, repetition of items, major commitment to interviewer training	Short, inexpensive Self-administered, postal and interview administered. Becoming the generic measure of choice. Widely used as a proxy measure. Multidimensional Response rates are high. Covers a wide range of areas affected by ill health.
Reliability	Test–retest technique reported as high [20] Sensitive to change [27]	Content validity is reduced, as pain is an important item; this symptom is uncommon in CHF.	High degree of validity in a number of populations [40,42,43]
Comments	Test–retest technique is high [21]. Interview administered score better than self-completed and postal version. Sensitive to change in clinical trials [21,36].	May lack sensitivity to symptoms experienced by patients with CHF [28–31].	Reported ceiling and floor effects in chronic diseases [46]
	Limited measure of function; some disabilities are not assessed. Requires supplementation if used as a broad measure of health-related quality of life. People who score zero cannot show improvement over time.	People need to be regarded or regard themselves as ill.	Insensitive to small clinical change which may be due to influences of comorbidity [56]

were missing responses associated with the questions on work and vigorous activity, frequently regarded as not applicable by elderly people [52]. Hayes et al. [52] surmised that people under 75 years old could usually complete the SF-36 without difficulty, but those older than 75 years may need assistance, especially if they have poor physical and mental health. It has been suggested that administration by interview may be the best way to use the SF-36 in the elderly population [53]. O'Mahony et al. [54] found that there was a high response rate to the SF-36 in older stroke patients when it was administered as a postal questionnaire. However, the poor completion rates in older stroke patients and consequent inability to compute scores for a large proportion of responders in certain scales raises concerns about the perceived relevance of these sections [54]. When data quality indicators were examined, it appeared that postal administration of the SF-36 is not appropriate for assessing quality of life in older stroke patients [54]. The use of an interviewer improves response, but factors which influence health status, such as physical and cognitive dysfunction, have a significant effect on response rates. Therefore, the usefulness of the SF-36 in a predominantly elderly heart failure population is questionable [55]. Comorbidity associated with elderly patients may also cause insensitivity to small clinical change [56].

An advantage of generic instruments is that they make it possible to compare outcomes across disease groups and different types of intervention. Health economists frequently employ these measures, as they can be used to guide resource allocation. However, these general measures are likely to be insensitive to change that is related to CHF.

4.2. Disease-specific measures

Researchers started to use specific measures of quality of life to increase the responsiveness of the measures to the patients being studied [16,57]. There are a number of types of specific measures: disease-specific, function-specific and informal measures. These can be used on their own or grouped together and used as batteries. Disease-specific instruments have been developed to be suitable to the problems associated with a specific medical condition, although they may have a narrow range of application [58]. A review of quality of life in cardiovascular disorders concluded that there are doubts about current concepts and measures [59]. HRQL measures have been poorly developed in relation to cardiovascular disease. CHD patients usually have other comorbid conditions, which generic instruments may not detect [56]. If only generic instruments such as the SF-36 are used to assess differences in, or changes to, HRQL in CHD patients, then the probability of making an incorrect conclusion is altered, in an unpredictable manner [56]. The majority of cardiology research has used inadequate HRQL measures [60], and until recently, very little work has been undertaken in CHF.

A comprehensive review of quality-of-life evaluations in CHF found there were important differences between different quality-of-life questionnaires [14]. This paper reviewed the design and validation of both generic and disease-specific quality-of-life questionnaires, which have been used in clinical trials of CHF. The aim of the review was to consider the impairment in quality of life that may occur in a patient with CHF. First, the authors reviewed the characteristics of a quality-of-life questionnaire, which would make it a useful instrument to evaluate quality of life in chronic heart failure. Second, they evaluated the performance of both generic and disease-specific quality-of-life questionnaires when used in clinical trials in CHF. They argue that quality of life is an opinion formed by a person's interpretation of their own health status in comparison to what they might hope to be able to achieve. This review concluded by saying that no instrument has measured quality of life in heart failure trials in a reliable or valid way, and therefore, an obvious need exists for the development of valid and reliable instruments [14].

There is no unified approach to the measurement of quality of life, and little agreement has been found on what it means [61]. There is no clear theoretical basis for quality-of-life measures, and this has created confusion and misunderstandings amongst researchers and practitioners with regard to which tool to use in research [62]. This has been echoed by a number of researchers who have studied quality of life and acknowledge that the conceptual ambiguity, doubtful validity and reliability, inappropriate methods and the weak statistical analyses of the data have restricted the use of quality-of-life measures [9,63].

Researchers have been encouraged to select a measure that is reported as being reliable, valid and easy to complete. However, they are faced with a substantial number of instruments to choose from in some areas and a famine of tools in other areas. It would seem that researchers are guided towards instruments more by fashion than efficacy; instruments are used indiscriminately by researchers because so many others have used them before [64]. However, generic instruments are generalisable to a large patient population, and these instruments will be used repeatedly in different studies to allow for comparability of the client population.

The choice of quality-of-life instrument should be based on issues relating to the ability to demonstrate reliability and validity to change over time or the psychometric properties of the measure [65]. Reliability is assessed in two ways: test-retest reliability and internal consistency. The former requires the administration of an instrument on two separate occasions to the same population. The correlation of scores provides an estimate of the reliability of the measure. It is usually determined using Pearson's correlation [66]. Internal consistency involves testing for homogeneity of the items contained in the questionnaire and is usually determined by Cronbach's alpha [66,67]; however, item homogeneity is often mistakenly believed to be equivalent to unidimensionality by researchers [68].

The validity of an instrument refers to its ability to measure what it is supposed to measure. There are four main forms of validity. Face validity refers to the researchers subjective assessment of the presentation and relevance of the questionnaire [66]. Content validity refers to the appropriateness of the content of the instrument to measure what it is intended to. Criterion validity is the correlation of the measure with another measure, which is valid. Construct validity refers to the ability of the instrument to measure the underlying concept it claims to measure [66].

Reliability and validity are not fixed qualities of an instrument—the fact that the reliability and validity of an instrument have been established in one population does not mean that it will be valid and reliable in other populations. Once the reliability and validity of a measure have been shown in one population, it must be reestablished in other populations [69–71].

Traditionally, in CHF, the New York Heart Association (NYHA) classification system has been used to assess functional status [72]. This scale assesses a combination of physical symptoms and limitations. The NYHA is the most widely used system, but it has been shown to be unresponsive to change, has a high degree of interobserver variability and the perspective is that of the doctor rather than of the patient [73].

4.3. Disease-specific measures in chronic heart failure

Disease-specific questionnaires are designed to obtain information about quality of life in patients with heart failure. There are several tools in this area, including the Quality of Life in Severe Heart Failure Questionnaire (QLQ-SHF; [74]), the Chronic Heart Failure Questionnaire (CHQ; [30]), the Kansas City Cardiomyopathy Questionnaire (KCCQ; [73]), the Left Ventricular Dysfunction Questionnaire (LVD-36; [75]) and the Minnesota Living with Heart failure Questionnaire (MLHFQ; [37,76]). According to the literature, the three most commonly used are the QLQ-SHF, CHQ and MLHFQ ([77,78]; Table 2).

4.3.1. *Quality of Life in Severe Heart Failure Questionnaire (QLQ-SHF)*

The QLQ-SHF [74] is a 26-item questionnaire which uses a Likert scale to quantify physical activities and a visual analogue scale to assess life satisfaction, social and emotional factors [14]. The higher the score, the greater the impairment of quality of life. The QLQ-SHF has been used in a number of clinical trials [79], and its validity was determined by correlations of the results from the questionnaire with those from comparable domains of the SIP. The construct validity is acceptable for the domains of psychological symptoms and life satisfaction. However, it is weak for the domains of somatic symptoms and physical limitations [14]. Results from these trials have shown that it is moderately sensitive to small changes in quality of life in patients with CHF [14]. However, there is no evidence to

suggest that this questionnaire is able to distinguish between patients with different severities of CHF, and therefore, this questionnaire needs to be explored and tested further in chronic heart failure [57].

4.3.2. *Chronic Heart Failure Questionnaire (CHQ)*

The CHQ [30] is a 20-item questionnaire, which was developed for use in CHF [14]. It is a complex questionnaire to administer. The questionnaire is administered by interview. It has three categories: dyspnoea, fatigue and emotional function. An increase in score shows an improvement in quality of life. This questionnaire was validated in a randomised, placebo-controlled trial of digoxin in CHF [80]. It was found to be most responsive to changes in dyspnoea and fatigue. The CHQ appears to be sensitive to patients with different severities of CHF.

4.3.3. *Minnesota Living with Heart Failure Questionnaire (MLHFQ)*

The MLHFQ [37] was designed specifically for use in heart failure. It assesses the patients' perception of the effects of CHF on the physical, socioeconomic and psychological aspects of their life. Patients respond to 21 items using a six-point Likert scale (0–5). It is also possible to obtain subscale scores for physical and emotional domains. The questionnaire is easy to administer, short and easily understood. It can be administered by interview, self-administered or by postal questionnaire. The measure has been found to be valid in comparison with other health outcome scales [14,81]. It has been shown to discriminate between patients with CHF and those with symptomatic left ventricular dysfunction. However, it does not distinguish well between different severities of CHF [14]. Test–retest technique found that initial low scores tended to increase and initial high scores tended to decrease. This suggests that regression to the mean is operating [82].

Concerns have been raised about the MLHFQ in terms of the patients ability to separate symptoms and impairments related to heart failure from other comorbidities [83]. The MLHFQ subscales may be less useful in quality-of-life assessment than the total score is [83]. Although the MLHFQ is the most popular measure, it should be noted that it was designed to be a patient self-assessment measure for use in clinical trials to assess the effects of drugs or devices, [83] and not as a complete quality-of-life assessment, thus, it is of value for some purposes, but not for others [37]. A recent study found the MLHFQ does not measure the concept that it is intended to measure [78].

5. Limitations of quality-of-life measures

Quality-of-life instruments have always been seen as long, time consuming and unresponsive assessment tools;

Table 2
Properties of disease-specific quality-of-life measures

Measure	Quality of Life in Severe Heart Failure Questionnaire [74]	Chronic Heart Failure Questionnaire [30]	Minnesota Living with Heart Failure Questionnaire [37]
Description	Measure of HRQL in patients with severe heart failure. Items were derived from existing scales and literature.	Measure of subjective health status in people with heart failure	Measures patients' perceptions of the effects of CHF on their daily lives.
Acceptability and appropriateness	Short. Self-administered. The scale's domains are summed to form an overall score. The higher the score the worse the patients.	Interview administered. Personal information is obtained from the participant in three categories of dyspnoea, fatigue and emotional function.	Lengthy. Well-trained interviewer. Complex to administer
Validity	Determined by correlation of the results with those from comparable domains of the SIP. Construct validity is acceptable for the domains of psychological symptoms and life satisfaction. Internal consistency is satisfactory [74].	Lack of a gold standard. Needs to be compared with other well-validated questionnaires. Construct validity is weak for domains of somatic symptoms and physical limitations.	Short, inexpensive, simple. Self-administered designed specifically for heart failure. Respondents must be instructed on how to complete it. Designed specifically for use in clinical trials.
Reliability	Test–retest technique is reported as high [74]. Trial of metoprolol detected improvements in the treatment group [79].	Unable to distinguish between different severities of heart failure.	Correlation has been reported with NYHA and patients self-rating [37]. Internal consistency has been found to be good [81].
Comments	Trial results suggest that the measure is moderately sensitive to small changes in quality of life in patients with CHF [14]. Needs to be used and tested further in CHF research [57]	The authors report reproducibility with 25 patients. Sensitive to different severities of CHF. Most sensitive to changes in dyspnoea and physical function.	Small numbers, needs confirmation. Test-retest technique reported no bias. Sensitivity to effects of medication. Regression to the mean has been found with scores [37]. Patients' ability to separate symptoms of heart failure and comorbidities may affect the usefulness of this measure.

but, since the introduction and availability of shorter, easier to understand and administer tools, there has been an increase in their use in clinical trials [22,41,46,84–88]. This reflects increasing interest in the need to know how the patient feels and how satisfied they are with their treatment. Although it has been recognised that these tools are reliable, they may not be relevant to individual patients; therefore, their validity may be suspect if they do not measure components of quality of life that are important to the patient. Many instruments are not derived from patient populations but from an expert medical viewpoint; yet, there is no guarantee that medical professionals understand patients' quality of life. Quality-of-life measures usually comprise a number of items to which patients respond. To maximise the relevance of these items, they should be derived, wherever possible, from a patient population. Many scales, e.g., the generic and disease-specific measures already described, were not derived from a patients' perspective. Instead, they relied on the perspective of professionals, and it may be the case that medical professionals may have a different view of the aspects of function that are important to quality of life [89].

A review of health-related quality of life questionnaires in CHF published in 1999 found 41 studies using instruments published between 1990 and 1998 [90]. Most commonly, such questionnaires were used in conjunction with clinical trials that tested the effectiveness of new medications or treatments. HRQL related to many domains, including disease state, physical and social functioning, social interaction and emotional state. The review found that 30 of the 41 studies were trials evaluating the effectiveness of a medication. The remaining studies focused on physical exercise, positive airway pressure, nurse case management and primary-care-related quality of life. In summary, no single general quality-of-life measure dominated the area of CHF, and three quarters of the studies were related to drug trials [90].

We would argue that quality of life can only be measured by determining the opinions of patients and using these in place of expert opinion. There may be factors that influence a patient's perception of quality of life that are individualised and cannot be expressed in a standard tool [89]. The individualised view of HRQL is not recognised or assessed by generic and disease-specific measures [91]. A qualitative approach to understanding everyday quality of life has the potential to provide powerful and detailed information about the context and contradictions that people with chronic clinical conditions experience [12]. A patient's self-assessment can differ substantially from the judgment of the doctor or of other healthcare staff [92,93]. Physicians tend to dramatically underestimate overall social functioning, role functioning and pain [93]. Discrepancies also exist between patients' measurements and patient narrative accounts [94], and in general, there are substantial discrepancies between patient and physician scores on the more subjective quality-of-life domains [93]. Practitioners are often surprised at the low value that patients attach to some aspects of quality of

life and the high value to others, which is at odds with the viewpoint of the practitioner [95]. Therefore, other factors are important in quality of life, which are not included in recognised measures. Most of the widely used measures are not patient centred and restrict a patient's choice; therefore, these limitations will reduce the accuracy and usefulness of expert-driven quality-of-life tools, as they do not measure what the patients feel contributes to their quality of life. Patient-centred outcome instruments allow the respondents to choose for themselves the areas of their lives that matter [89]. Many of the tools for measuring quality of life are based on a health status model that focuses mainly on objective measures, and less attention has been paid to subjective forms of assessment [12]. Quality-of-life tools in CHF do not measure quality of life in a reliable or valid fashion [14].

6. Rationale for a new approach

Quality-of-life measures are not aimed at the correct target, unless an opportunity to express patients opinions and reactions is provided [61]. Quality of life is a personal perception, which shows the way an individual feels about their health and/or the nonmedical aspects of their lives [61]. Most measures of quality of life in the literature impose standard models of quality of life and preselected domains on the individual. Many of the measures force an external value system on individuals rather than allowing them to describe their lives in ways that they themselves find important [63]. What differentiates quality of life from other measures is the need to obtain and integrate the patients' values and perceptions into the assessment [61]. We understand quality of life from a variety of indicators, many of which tell us about life, but not about quality.

Assessing the patients' experience of CHF and its treatment is a central component of health care. Quality-of-life measures capture the personal and social context of patients [96]. Measures that have been developed for clinical research cannot be easily used in clinical practice. There is increasing interest in developing individualised tools that reflect the perception that quality of life is unique to individuals and cannot be adequately assessed using standardised measures [96].

7. Conclusion

A valid measure of quality of life should be defined in individual terms; therefore, there is a caveat to current quality-of-life measures for use in CHF, as their meaning and relevance to the target population are suspect. Generic measures produce an overall representation of a patients' assessment of their quality of life. The imprecise nature of these measures may cover a particular aspect that may be of major importance to the patient, therefore limiting their use.

The measure must focus less on functional disability and include aspects of life that give it meaning and purpose. Physiological measurements of health status describe only limited aspects of the individuals' life and may not have meaning and relevance in the context of that life [97]. The subjective and individualistic nature of quality of life has been defined as “the extent to which our hope and ambitions are matched by experience” [97].

Most of the measures were designed for use in clinical research and are therefore not necessarily appropriate for clinical practice. It is not the intention of this review to provide a solution to this limitation. However, further research is required to look at patient-led quality-of-life measures in everyday practical care in a chronic heart failure population.

References

- [1] Kelly D. Our future society: a global challenge. *Circulation* 1997;95:2459–64.
- [2] Stewart S, Blue L. Improving outcomes. Chronic heart failure. London: BMJ Books; 2001.
- [3] Cowie M, Kirby M. Heart failure: an overview. Managing heart failure in primary care: a practical guide. Oxfordshire: Bladon Medical Publishing. p. 1–5.
- [4] Stewart S, MacIntyre K, Hole D, Capewell S, McMurray J. More “malignant” than cancer? *Eur J Heart Fail* 2001;3:315–22.
- [5] Rich M, Beckham V, Wittenberg C, Leven C, Freeland K, Carney R. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. *N Engl J Med* 1995;333:1190–5.
- [6] Dracup K, Walden J, Stevenson L, Bracht M. Quality of life in patients with advanced heart failure. *J Heart Lung Transplant* 1992;11:273–9.
- [7] McMurray J, Stewart S. Epidemiology, aetiology and prognosis of heart failure. *Heart* 2000;83(5):596–602.
- [8] MacIntyre K, Capewell S, Stewart S. Evidence of improving prognosis in heart failure: trends in case fatality in 66,547 patients hospitalised between 1986 and 1995. *Circulation* 2000;102:1126–31.
- [9] Fallowfield L. Quality of life data. *Lancet* 1996;348:421–2.
- [10] Wilson I, Cleary P. Linking clinical variables with health related quality of life. *JAMA* 1995;273(1):59–65.
- [11] Deyo R. The quality of life, research and care. *Ann Intern Med* 1991;114(8):695–7.
- [12] Nicolson P, Anderson P. Quality of life, distress and self-esteem: a focus group study of people with chronic bronchitis. *Br J Health Psychol* 2003;8:251–70.
- [13] Thompson D, Yu C. Quality of life in patients with coronary heart disease: I. Assessment tools. *Health Qual Life Outcomes* 2003;1(1):42.
- [14] Berry C, McMurray J. A review of quality of life evaluations in patients with congestive heart failure. *Pharmacoeconomics* 1999;16(3):247–71.
- [15] Murberg T, Bru E, Svebak S, Tveteras R, Aarsland T. Depressed mood and subjective health symptoms as predictors of mortality in patients with congestive heart failure: a two years follow up study. *Int J Psychiatry Med* 1999;29(3):263–358.
- [16] Guyatt G, Feeny D, Patrick D. Measuring health-related quality of life. *Ann Intern Med* 1993;118(8):622–9.
- [17] Bennett S, Oldridge N, Eckert G, Embree J, Browning S, Hou N, et al. Discriminant properties of commonly used quality of life measures in heart failure. *Qual Life Res* 2002;11:349–59.
- [18] Barnett D. Assessment of quality of life. *Am J Cardiol* 1991;67:41C–4C.
- [19] Gill T. Quality of life assessment: values and pitfalls. *JR Soc Med* 1995;88:680–2.
- [20] Hunt S, McEwen J, McKenna S. Measuring health status. London: Croom Helm; 1986.
- [21] Bergner M, Bobbitt R, Carter W, Gilson B. The Sickness Impact Profile: development and final revision of a health status measure. *Med Care* 1981;19:787–805.
- [22] Ware J, Sherbourne C. The MOS 36 item short form health survey (SF-36): I. Conceptual framework and item selection. *Med Care* 1992;30:473–83.
- [23] Anderson R, Aaronson N, Wilkin D. Critical review of the international assessments of health related quality of life. *Qual Life Res* 1993;2:369–95.
- [24] Hubanks L, Kuyken W. Quality of life assessment: an annotated bibliography. Geneva: World Health Organization, Division of Mental Health.
- [25] O'Brien B. Assessment of treatment in heart disease. In: Teeling Smith G, editor. Measuring health: a practical approach. Chichester: John Wiley; 1988.
- [26] O'Brien B, Banner N, Gibson S. The Nottingham Health Profile as a measure of quality of life following combined heart and lung transplantation. *J Epidemiol Community Health* 1988;42:232–4.
- [27] Jenkinson C, Fitzpatrick R, Argyle M. The Nottingham Health Profile: an analysis of its sensitivity in differentiating illness groups. *Soc Sci Med* 1988;27:1411–4.
- [28] Ekeberg O, Klemsdal T, Kjeldsen S. Quality of life on enalapril after acute myocardial infarction. *Eur Heart J* 1994;15(8):1135–9.
- [29] Cowley A, Skene A. Treatment of severe heart failure: quantity or quality of life? *Br Heart J* 1994;72:226–30.
- [30] Guyatt G, Nogradi S, Harlow S, Sullivan M, Fallen E. Development and testing of a new measure of health status for clinical trials in heart failure. *J Gen Intern Med* 1989;4:101–7.
- [31] Johnson P, Cowley A, Kinnear W. A randomised controlled trial of respiratory muscle training in stable chronic heart failure. *Eur Heart J* 1998;19:1249–53.
- [32] Wallwork J, Caine N. A comparison of the quality of life of cardiac transplant patients and coronary artery bypass graft patients before and after surgery. *Qual Life Cardiovasc Care* 1995;1:317–31.
- [33] Pollard W, Bobbitt R, Bergner M. The Sickness Impact Profile: reliability of a health status measure. *Med Care* 1976;14:57–67.
- [34] De Bruin A, De Witte L, Stevens F, Diederiks J. Sickness Impact Profile: the state of the art of a generic functional status measure. *Soc Sci Med* 1992;35(8):1014–33.
- [35] Katz S, Ford A, Mowat A. Studies of illness in the aged: the index of ADL. *JAMA* 1963;185:914–9.
- [36] Ware J, Kosiniski M, Keller S. SF-12: how to score the SF-12 Physical and Mental Health Summary Scales. 2nd ed. Boston: The Health Institute, New England Medical Centre; 1995.
- [37] Rector T, Kubo S, Cohn J. Patients self-assessment of their congestive heart failure: content, reliability and validity of a new measure—the Minnesota Living with Heart Failure Questionnaire. *Heart Fail* 1987;3:198–209.
- [38] Bulpitt C, Fletcher A, Dossenger L, Neilsen T, Viergutz S. Quality of life in chronic heart failure: cilazapril and captopril versus placebo. *Heart* 1998;79:593–8.
- [39] Rector T, Francis G, Cohn J. Patients' self-assessment of their congestive heart failure. *Heart Fail* 1987;3:198–209.
- [40] Brazier J, Harper R, Jones N, O'Cathain A, Thomas K, Usherwood T, et al. Validating the SF-36 health survey questionnaire: new outcome measures for primary care. *BMJ* 1992;305:160–4.
- [41] McHorney C, Ware J, Raczek A. The MOS 36 item short form health survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health conditions. *Med Care* 1993;31(3):247–63.
- [42] Garratt A, Ruta D, Abdalla M, Buckingham J, Russell I. The SF-36 health survey questionnaire: an outcome measure suitable for routine use within the NHS? *BMJ* 1993;306:1440–4.

- [43] Jenkinson C, Coulter A, Wright L. Short form 36 (SF-36) health survey questionnaire: normative data for adults of working age. *BMJ* 1993;306:1437–40.
- [44] Jenkinson C, Layte R, Wright L, Coulter A. The U.K. SF-36: an analysis and interpretation manual. Health Services Research Unit, Department of Public Health and Primary Care. Oxford: University of Oxford; 1996.
- [45] Bowling A, Bond M, Jenkinson C, Lamping D. Short Form 36 (SF-36) Health Survey Questionnaire: which normative data should be used? Comparisons between the norms provided by the omnibus survey in Britain, the health survey for England and the Oxford Healthy Life Survey. *J Public Health Med* 1999;21:255–70.
- [46] McHorney C, Ware J, Lu J. The MOS short form health survey (SF-36): III. Tests of data quality, scaling assumptions and reliability across diverse patient groups. *Med Care* 1994;32:40–66.
- [47] Ware J, Kosiniski M, Keller S. A 12-item Short-Form Health Survey (SF-12): construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34:220–33.
- [48] Garratt A, Ruta D, Abdalla M, Russell I. SF-36 health survey questionnaire: II. Responsiveness to changes in health status in four common clinical conditions. *Qual Health Care* 1994;3:186–92.
- [49] DoH. The national service framework for coronary heart disease. London: Department of Health; 2000.
- [50] McMurray J, Hart W, Rhodes G. An evaluation of the cost of heart failure to the national health service in the UK. *Br J Med Econ* 1993;6:99–110.
- [51] Parameshwar J, Shackell M, Richardson A, Poole-Wilson P, Sutton G. Prevalence of heart failure in three general practices in North West London. *Br J Gen Pract* 1992;42:287–9.
- [52] Hayes V, Morris J, Wolfe C, Morgan M. The SF-36 health survey questionnaire: is it suitable for use with older adults? *Age Ageing* 1995;24:120–5.
- [53] Lyons R, Perry H, Littlepage B. Evidence for validity of the short form 36 questionnaire (SF-36) in an elderly population. *Age Ageing* 1994;23:182–4.
- [54] O'Mahony P, Rodgers H, Thompson R, Dobson R, James O. Is the SF-36 suitable for assessing health status of older stroke patients? *Age Ageing* 1998;27:19–22.
- [55] Parker S, Peet S, Jagger C, Farhan M, Castleden C. Measuring health status in older patients. The SF-36 in practice. *Age Ageing* 1998;27:13–8.
- [56] Spertus J, Winder J, Dewhurst T, Deyo R, Fihn S. Monitoring the quality of life in patients with coronary artery disease. *Am J Cardiol* 1994;74:1144–240.
- [57] Nanda U, Andresen E. Health related quality of life: a guide for health professionals. *Eval Health Prof* 1998;21(2):179–215.
- [58] Guyatt G, Bombardier C, Tugwell P. Measuring disease specific quality of life in clinical trials. *Can Med Assoc J* 1986;134:889–95.
- [59] Mayou R. Quality of life in cardiovascular disorders. *Psychother Psychosom* 1990;54:99–109.
- [60] Mayou R, Bryant B. Quality of life in cardiovascular disease. *BMJ* 1993;69:460–6.
- [61] Gill T, Alvan R, Feinstein A. A critical appraisal of the quality of quality of life measurements. *JAMA* 1994;272(8):24–31.
- [62] Leplege A, Hunt S. The problem of quality of life in medicine. *JAMA* 1997;278(1):47–50.
- [63] O'Boyle C, McGee H, Joyce C. Quality of life: assessing the individual. *Adv Med Sociol* 1994;5:159–80.
- [64] Donovan J, Frankel S, Eyles J. Assessing the need for health status measures. *J Epidemiol Community Health* 1992;47:158–62.
- [65] Draper P, Thompson D. The quality of life—a concept for research and practice. *NT Res* 2001;6(3):648–57.
- [66] Bowling A. The principles of research. Research methods in health: investigating health and health services. Buckingham, Philadelphia: Open Univ. Press; 2002. p. 134–62.
- [67] Traub R. Reliability for the social sciences: theory and applications. California: Sage; 1994.
- [68] Shevlin M, Miles J, Davies M, Walker S. Coefficient alpha: a useful indicator of reliability? *Pers Individ Differ* 2000;28(2):229–38.
- [69] Vacha-Haase T. Reliability generalization: Exploring variance in measurement error affecting score reliability across studies. *Educ Psychol Meas* 1998;58(1):6–20.
- [70] Vacha-Haase T. Reliability generalization: Exploring variance in measurement error affecting score reliability across studies. *Educ Psychol Meas* 1998;58:6–20.
- [71] Miles J, Shevlin M, McGhee P. Examining gender differences in reliability of the EPQ: a bootstrapping approach. *Br J Psychol* 1999;28(2):145–54.
- [72] Goldman L, Hashimoto B, Cook E, Loscalzo A. Comparative reproducibility and validity of systems for assessing cardiovascular functional class: advantages of a new specific scale. *Circulation* 1981;64(6):1227–34.
- [73] Green C, Porter C, Bresnahan D, Spertus J. Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. *J Am Coll Cardiol* 2000;35(5):1245–55.
- [74] Wiklund I, Lindvall K, Swedberg K. Self assessment of quality of life in severe heart failure. *Scand J Psychol* 1987;28:220–5.
- [75] O'Leary C, Jones P. The left ventricular dysfunction questionnaire (LVD-36): reliability, validity and responsiveness. *Heart* 2000;83:634–40.
- [76] Riegel B, Moser D, Glaser D, Carlson B, Deaton C, Armola R, et al. The Minnesota Living with Heart Failure Questionnaire: sensitivity to differences and responsiveness to intervention intensity in a clinical population. *Nurs Res* 2002;51(4):209–18.
- [77] Johansson P, Agnebrink M, Dahlstrom U, Brostrom A. Measurement of health-related quality of life in chronic heart failure, from a nursing perspective—a review of the literature. *Eur J Cardiovasc Nurs* 2004;3:7–20.
- [78] Hak T, Willems D, van der Wal G, Visser F. A qualitative validation of the Minnesota Living with Heart Failure Questionnaire. *Qual Life Res* 2004;14:417–26.
- [79] Wiklund I, Waagstein F, Swedberg K, Hjalmarsson A. Quality of life on treatment with metoprolol in dilated cardiomyopathy: results from the MDC trial. *Cardiovasc Drugs Ther* 1996;10:361–8.
- [80] Guyatt G, Sullivan M, Fallen E, Tihal H, Rideout E, Halcrow S, et al. A controlled trial of digoxin in congestive heart failure. *Am J Cardiol* 1988;61(4):371–5.
- [81] Gorkin L, Norvell N, Rosen R. Assessment of quality of life as observed from the baseline data of the studies of left ventricular dysfunction trial quality of life substudy. *Am J Cardiol* 1993;71:1069–73.
- [82] Bowling A. Cardiovascular disease. Measuring disease. Buckingham, Philadelphia: Open Univ. Press, 1995. p. 234–58.
- [83] Sneed N, Paul S, Michel Y, VanBakel A, Hendrix G. Evaluation of 3 quality of life measurement tools in patients with chronic heart failure. *Heart Lung* 2001;30(5):332–40.
- [84] Parkerson G, Broadhead W, Tse C. The Duke Health Profile: a 17 item measure of health and dysfunction. *Med Care* 1990;28:1056–72.
- [85] Hunt S, McEwen J, McKenna S. Measuring health status: a new tool for clinicians and epidemiologists. *J R Coll Gen Pract* 1985;185–8.
- [86] Nelson E, Wasson J, Krik J. Assessment of function in routine clinical practice: description of the COOP chart method and preliminary findings. *J Chronic Dis* 1987;40:55S–63S.
- [87] Stewart A, Hays R, Ware JJ. The MOS short form general health survey: reliability and validity in a patient population. *Med Care* 1988;26:724–35.
- [88] McHorney C, Ware J, Ragers W, Raczek A, Lu J. The validity and relative precision of MOS short and long form health status scales and Dartmouth COOP charts. *Med Care* 1992;30:MS253–65.
- [89] Paul S, Sneed N. Patient perceptions of quality of life and treatment in an outpatient congestive heart failure clinic. *Congest Heart Fail* 2001;8(2):74–9.

- [90] Leidy N, Rentz A, Zyczynski T. Evaluating health related quality of life outcomes in patients with congestive heart failure: a review of recent randomised controlled trials. *Pharmacoeconomics* 1999;15(1): 19–46.
- [91] Dempster M, Donnelly M, Fitzsimons D. Generic, disease-specific and individualised approaches to measuring health-related quality of life among people with heart disease—a comparative analysis. *Psychol Health* 2001;17(4):447–57.
- [92] Slevin M, Plant H, Lynch D, Drinkwater J, Gregory W. Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988;57:109–12.
- [93] Wilson K, Dowling A, Abdolell M, Tannock I. Perception of quality of life by patients, partners and treating physicians. *Qual Life Res* 2000;9:1041–52.
- [94] Campbell R, Quilty B, Dieppe P. Discrepancies between patients' assessments of outcome: qualitative study nested within a randomised controlled trial. *Br Heart J* 2003;326:252–3.
- [95] Williams A. Do we really need to measure quality of life? *Br J Hosp Med* March 1988; 181.
- [96] Higginson I, Carr A. Using quality of life measures in the clinical setting. *BMJ* 2001;322:1297–300.
- [97] Calman K. Quality of life in cancer patients—an hypothesis. *J Med Ethics* 1984;10:124–7.