



Instruments to assess quality of life in patients with heart failure

Instrumentos de avaliação da qualidade de vida em pacientes com insuficiência cardíaca

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Abstract

Introduction: Heart failure (HF) is a complex clinical syndrome representing the common final pathway of various heart diseases. It is characterized by low exercise tolerance, low survival rates and deteriorated quality of life. Several studies mention Quality of Life (QoL) as an important source of information on how disease truly affects patient's lives. In this context, the assessment of QoL is extremely important to provide data that support the choice of a therapeutic strategy and the assessment of the effectiveness of a treatment. **Objectives:** This study aimed to investigate and identify the most appropriate and widely used instrument for the assessment of quality of life in patients with HF. **Methods:** We searched the databases of Lilacs, Medline, Pubmed, Scielo and CAPES to identify relevant articles published in English and Portuguese between 2000 and 2010. **Results:** We found 25 papers that described, quoted or used instruments for the assessment of QoL in patients with HF. **Conclusion:** The MLHFQ is the most widely used instrument to assess QoL in patients with HF. Its good metric properties have been confirmed in a large number of studies. In

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addition, it has a simple structure and is easy to administer, which makes it the most recommended instrument for this purpose.

Keywords: Questionnaires. Quality of Life. Heart failure.

Resumo

Introdução: A insuficiência cardíaca é uma complexa síndrome clínica, via final comum de várias cardiopatias, podendo ser caracterizada por baixa tolerância ao exercício, baixa sobrevida e qualidade de vida deteriorada. A Qualidade de vida (QV) vem sendo mencionada em diversos estudos como uma importante fonte de informação sobre como a doença realmente afeta a vida dos indivíduos doentes. Nesse contexto, a avaliação da QV é de fundamental importância para fornecer dados que auxiliem na decisão de uma estratégia terapêutica e na avaliação da eficácia de um tratamento realizado. **Objetivos:** Os objetivos desse estudo foram identificar e determinar o instrumento mais utilizado e adequado na avaliação da qualidade de vida em pacientes com IC. **Metodologia:** Foi feito levantamento bibliográfico, nos idiomas inglês e português, nas bases de dados Lilacs, Medline, Pubmed, Scielo, CAPES, no período entre 2000 e 2010. **Resultados:** Foram encontrados 25 trabalhos que descreviam, citavam ou utilizavam os instrumentos de avaliação da QV em pacientes com IC. **Conclusão:** Dentre os instrumentos de avaliação da QV descritos para pacientes com IC, o mais utilizado é o MLHFQ, tendo em vista suas boas propriedades métricas, que foram demonstradas em um grande número de estudos, além de possuir estrutura simples e de fácil administração, portanto mais recomendável.

Palavras-chave: Questionários. Qualidade de vida. Insuficiência cardíaca.

Introduction

Heart failure (HF) is a complex clinical syndrome initiated by the inability of the heart to pump blood at a rate commensurate with the metabolic demands of the body, i.e., the heart cannot supply the body's tissues with enough blood to ensure nutrition and proper removal of waste products. HF may be caused by myocyte dysfunction or loss, ventricular remodeling or by a combination of both (1). Thus, HF is the common final pathway of all heart diseases and is characterized by increased neurohormonal activity, low exercise tolerance, low survival rates and deteriorated quality life (2, 3).

Quality of life (QoL) quality of life is "the individual's perception of his/her position in life, within the context of culture and value systems in which he/she lives and in relation to his/her objectives, expectations, standards and concerns" (4), i.e., it is a discrepancy between satisfaction and dissatisfaction with certain areas of life, according to the individual's perception, and this perception is considered the best indicator of QoL (5). In conventional language, life

satisfaction refers to the fulfillment of needs, expectations, desires and wishes (2).

Health-related QoL assessments are designed to focus on the patient's own experience or interpretation of how he/she is functioning in relation to illness, i.e., they define the patient's reality, his/her point of view as opposed to the reality defined by professional medical knowledge. (6, 7).

The objective of QoL measurements is to identify how the disease affects the QoL of patients and how patients face and cope with their situation. Thus, QoL assessment is an important source of information, in addition to diagnostic and laboratory tests, and its use in controlled clinical trials has been growing steadily over time (8, 9, 10). Accordingly, there is an effort of the scientific community to quantify the impact of HF on patients' lives. In this context, the assessment of QoL is extremely important to provide data that support the choice of a therapeutic strategy and the assessment of the effectiveness of a treatment.

This study aimed to investigate and identify the most appropriate and widely used instrument for the assessment of quality of life in patients with HF.

Materials and methods

The databases of Lilacs, Medline, Pubmed, Scielo and CAPES were searched for relevant articles published in English and Portuguese between 2000 and 2010, using the following key words: heart failure, quality of life and questionnaires. In addition, a general review was conducted on books and manuals that addressed QoL in patients with HF.

Articles that described, quoted or used instruments for the assessment of QoL in patients with HF were included in this study. Studies addressing instruments that did not meet the functional and symptomatic characteristics of HF were excluded.

Results

We found 25 papers that described, quoted or used instruments for the assessment of QoL in patients with HF. These are described in the Table 1.

Table 1 - Summary and description of the questionnaires found in the literature search

(to be continued)

Instrument name	Description
<i>Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)</i>	This instrument is composed of 36 items grouped into eight subscales: physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality, social functioning, role emotional and mental health. The SF-36 assesses negative health aspects (such as diseases or illnesses) as well as positive ones (such as well-being) (11).
<i>Nottingham Health Profile</i>	This self-administered questionnaire consists of 38 items, based on the WHO (World Health Organization) classification of disabilities. The items are organized into six categories: energy level, pain, emotional reactions, sleep, social interaction and physical abilities. Each positive response corresponds to a score of one (1) and each negative response corresponds to a score of zero (0), giving a maximum score of 38 (12).

Table 1 - Summary and description of the questionnaires found in the literature search

(to be continued)

Instrument name	Description
<i>Sickness Impact Profile</i>	This questionnaire consists of 136 items addressing the following areas of the patient's life: walking, self-care, mobility, emotional behavior, work, sleep, eating, household management and recreational activities (11).
<i>Minnesota Living Heart Failure Questionnaire (MLHFQ)</i>	This questionnaire is composed of 21 questions relating to limitations in lifestyle associated with HF. Respondents use a 5-point scale that ranges from 0 (none) to 5 (too much), with a score of 0 representing no limitation and a score of 5 representing maximum limitation. The total score is computed by adding the individual scores of questions involving a physical dimension highly interrelated with dyspnea and fatigue; an emotional dimension and other questions (2, 13).
<i>Kansas City Cardiomyopathy Questionnaires (KCCQ)</i>	This questionnaire consists of 23 items that quantify physical function, HF-specific symptoms, (such as swelling, dyspnea, fatigue), QoL, social impact of the disease and self-efficacy (14).
<i>Quality of life in Severe Heart Failure Questionnaire (QLQ-SHF)</i>	This questionnaire consists of 26 items quantifying the level of physical activity of respondents and an analogue visual scale evaluating life satisfaction according to social and emotional aspects. The higher the score, the greater the impairment of QoL (15).
<i>Euro Heart Failure Quality of Life Questionnaire</i>	This instrument incorporates the assessment of functional status with a wide range of questions related to health status and QoL that are relevant to HF. It consists of 40 questions about: fatigue, dyspnea, edema of the ankles, appetite, sleep, depression, mobility and social activities. Different aspects of a patient's life are assessed in relation to his/her perception of health and overall QoL. The higher the score, the better the quality of life (16).

Table 1 - Summary and description of the questionnaires found in the literature search

(conclusion)

Instrument name	Description
<i>Chronic Heart Failure Questionnaire (CHQ)</i>	This questionnaire consists of 20 items, divided into 3 categories: dyspnea, fatigue and emotional function. An increase in score indicates better QoL. It allows the assessment of different types of dyspnea and fatigue, as well as different degrees of HF severity (17).

Discussion

QoL questionnaires provide a more complete assessment of the impact of disease and treatment on the daily life of patients. They must be able to identify the presence of disease and reflect the evolutionary changes resulting from treatment, either due to its beneficial effect or due to its side effects (18). The instruments studied in this paper are used for the assessment of QoL in patients with HF and either globally or specifically evaluate the most important aspects related to a person's quality of life. As there are many instruments, there are also advantages and disadvantages in their administration.

The advantage of generic instruments is that a single instrument can be used to effectively detect changes in different aspects of patients' health status and allow for comparisons across diverse conditions and interventions (19). Their disadvantage is that they do not measure the specific problems of a disease and may not be sensitive enough to be able to detect small but important changes, due to their generic character (20). In this review, the following generic instruments were used to assess the QoL in patients with HF: *Sickness Impact Profile, Nottingham Health Profile, Medical Outcomes Study 36-Item Short-Form Health Survey*.

Because of the disadvantages of generic instruments, specific QoL instruments have been created to individually and specifically assess certain aspects of QoL and disease in a given population (HF) or for a particular function. Specific instruments have the advantages of being more responsive to changes in QoL that occur in a given period of time and of being more sensitive in discriminating the range of impairment

in QoL because of their focus on the most relevant aspects of QoL for the problem assessed. (19). In this paper, the following HF-specific instruments were found: *Chronic Heart Failure Questionnaire, Euro Heart Failure Quality of Life Questionnaire, Quality of life in Severe Heart Failure Questionnaire, Kansas City Cardiomyopathy Questionnaires e Minnesota Living Heart Failure Questionnaire*.

QoL instruments alone can detect important aspects of the impact of a disease on QoL. Moreover, when used alone, they have the disadvantages of not allowing comparisons between different situations, being limited in some situations and interventions, and of being restricted to areas relevant to a certain disease, population (20) or function (16).

The Minnesota Living Heart Failure Questionnaire (MLHFQ) is currently the most commonly used specific instrument for assessing health-related QoL. It was validated and translated into Brazilian Portuguese by Carvalho in 2009 (2). The widespread use of this instrument and the larger amount of data available particularly caught our attention (21, 22, 23). Scattolin *et al.* (2007) state that there is an inverse relationship between health-related QoL and functional independence, as measured by the MLHFQ (24, 25). Although the MLHFQ is currently the most popular specific instrument to measure QoL, it should be noted that it was originally designed to be a self-assessment tool for patients and a useful measure in clinical trials or to evaluate the effects of drugs or devices, and not to be used as a full instrument to assess QoL. Therefore, it is a valuable tool for some purposes, but not for others (15, 17, 26, 27).

Another widely used instrument for the assessment of QoL in patients with HF is the Chronic Heart Failure Questionnaire (CHQ). According to Doris (2002), the CHQ is a highly acceptable instrument to measure HF-specific quality of life and social support in Chinese populations (28). The same author also states that the CHQ is a valid and reliable instrument to measure QoL in cardiac patients.

Dunderdale *et al.* (2005) also reports that the CHQ is complex to administer, but this questionnaire has been designed to be the most sensitive to changes in dyspnea and fatigue, and seems to be sensitive to different severities of HF (16, 29).

Another specific instrument used to assess QoL in patients with HF is the Euro Heart Failure Quality of Life Questionnaire. Unlike the CHQ-C, this instrument,

which incorporates the assessment of functional status, evaluates a number of issues related to health and QoL, focusing more on perceived health and overall QoL (16, 30, 31).

The Kansas City Cardiomyopathy Questionnaires (KCCQ) quantifies physical limitation and QoL, and has proven to be a valid and reliable instrument. In addition, it seems to be very sensitive in monitoring the clinical course of patients (32). It has been used in several international studies and no differences in its administration and validation were found between countries (32, 33). According to Leal *et al.* (2010), the KCCQ allows for a direct quantification (in the clinical setting) of the benefits perceived by patients in relation to the interventions to which they are subjected, which eliminates inter-observer variability. Moreover, this instrument shows excellent sensitivity to changes in clinical condition over time, which has been observed over three months in a group of patients undergoing clinical intervention for HF (14).

The Quality of life in Severe Heart Failure Questionnaire (QLQ-SHF) has been used in several clinical trials and its validity was determined by comparing the QLQ-SHF scores with comparable areas of the Sickness Impact Profile (SIP) (15). Dunderdale *et al.* (2005) claims that there is no evidence to suggest that the QLQ-SHF is able to distinguish between different severities HF and that, although this instrument shows a good correlation with the SIP, it needs to be further investigated and tested to be used in the assessment of patients with chronic heart failure (34). The SIP is a generic instrument and therefore shows variable results in improving QoL in intervention groups. This may be due to its lack of sensitivity to changes in QoL in patients with HF. Studies also suggest that the SIP does not discriminate adequately between varying HF severity degrees. Thus, none of the two instruments mentioned above produce accurate results for the assessment of QoL in patients with HF (33, 34).

Another generic instrument used to assess QoL in patients with HF is the Nottingham Health Profile (NHP). This instrument measures perceived anxieties relating to serious disabling diseases (15). It has been originally developed using the public perception of health and provides a description of how people feel when they are sick. However, it has been used in a number of clinical trials in heart failure and produced variable results. This may have been due to its lack

of sensitivity to symptoms experienced by patients with HF and to its inability to detect disease at lower stages. Thus, small improvements over time are not detected. Therefore further studies are needed on the validity and use this instrument in patients with HF (15). According to Salmela *et al.* (2004), the NHP presents problems regarding its clinical validity, because the scale is too easy and does not measure the entire continuum of QoL (12). Furthermore, the questionnaire discriminates little between patients, as individuals are only divided into two skill levels. This indicates that it could be more useful when administered to more debilitated individuals. In order to be administered to more functionally capable individuals, the scale should be reviewed and more difficult items should be included. Therefore, despite being simple and easy to use, it is essential that this questionnaire is used in association with a functional assessment and/or a semi-structured interview in order to make the collected information more useful clinically (12).

Last but not least, the SF-36 was another generic instrument used for the assessment of patients with HF. This assessment tool is widely used, being the most commonly used instrument to compare specific instruments with generic instruments. It is a widely used instrument in many countries and can be found in the literature in many different languages (16). Studies also indicate that this instrument has high correlation with the classification of New York Heart Association (NYHA) (35). However, it was found that the SF-36 is more sensitive to smaller degrees of QoL impairment. The SF-36 is suitable for use in heart failure trials, especially when used in conjunction with a HF-specific instrument (15, 36, 37, 38).

According Wann-Hansson (2004), who compared QoL in patients with chronic ischemia of the lower limbs as measured by the NHP and SF-36, the SF-36 produces less distorted and more homogeneous results, and shows greater internal consistency, except for social functioning one year postoperatively. Nevertheless, it was more sensitive in detecting changes over time in patients with intermittent claudication (39).

According to Garin *et al.* (2009), the questionnaire should be selected according to the objectives of the study, because each instrument has its own characteristics. For example, in certain situations a method that also admits of self-administration may be preferable, therefore, the ideal choice would be

between the MLHFQ and the KCCQ, whereas the MLHFQ or CHFQ would be more appropriate for use in longitudinal studies. Despite the fact that all the specific instruments have been specifically developed to assess patients with HF, the various questionnaires have specific dimensions, which may be of particular interest in some studies (40).

With regard to the general measures, according Leal et al. (2010), although they are valid and reliable, they also show some problems regarding: a) poor sensitivity to small changes in the symptoms (NHP, SIP and SF-36); b) assessment of domains that cannot be directly translated to HF patients (such as pain assessment in the NHP); c) assessment of domains that are inconsistent with the age group analyzed (such as question about violent exercise and its employment in patients over 75 years, as assessed by the SF-36 in HF patients, due to the high incidence and prevalence of this condition in elderly patients). Regarding the specific measures, the authors report that, despite the validity and reliability of most specific questionnaires, they show some problems regarding: a) the identification of the severity of HF (as observed in the QLQ-SHF and MLHFQ); b) their complexity, which makes them difficult to administer to patients (as is the case of the CHQ); c) their suitability for assessment of QoL beyond the setting of clinical trials (as is the case of the MLHFQ) (14, 19).

Thus, when choosing an instrument to assess QoL in a patient with heart failure, several practical and methodological considerations must be made. The instruments should be used for a specific purpose, be validated in individual patients or in a population of patients, be understandable, reproducible, valid and sensitive to changes, as well as easy to administer in a timely manner and adapted for use by other researchers.

Conclusion

The MLHFQ is the most widely used instrument to assess QoL in patients with HF. Its good metric properties have been confirmed in a large number of studies. In addition, it has a simple structure and is easy to administer, which makes it the most recommended instrument for this purpose.

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Received: 04/25/2011

Recebido: 25/04/2011

Approved: 05/12/2014

Aprovado: 12/05/2014