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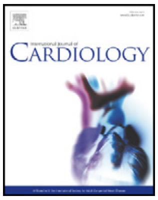

Review

The patient perspective: Quality of life in advanced heart failure with frequent hospitalisations

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ABSTRACT

End of life is an unfortunate but inevitable phase of the heart failure patients' journey. It is often preceded by a stage in the progression of heart failure defined as advanced heart failure, and characterised by poor quality of life and frequent hospitalisations. In clinical practice, the efficacy of treatments for advanced heart failure is often assessed by parameters such as clinical status, haemodynamics, neurohormonal status, and echo/MRI indices. From the patients' perspective, however, quality-of-life-related parameters, such as functional capacity, exercise performance, psychological status, and frequency of re-hospitalisations, are more significant. The effects of therapies and interventions on these parameters are, however, underrepresented in clinical trials targeted to assess advanced heart failure treatment efficacy, and data are overall scarce. This is possibly due to a non-universal definition of the quality-of-life-related endpoints, and to the difficult standardisation of the data collection. These uncertainties also lead to difficulties in handling trade-off decisions between quality of life and survival by patients, families and healthcare providers. A panel of 34 experts in the field of cardiology and intensive cardiac care from 21 countries around the world convened for reviewing the existing data on quality-of-life in patients with advanced heart failure, discussing and reaching a consensus on the validity and significance of quality-of-life assessment methods. Gaps in routine care and research, which should be addressed, were identified. Finally, published data on the effects of current i.v. vasoactive therapies such as inotropes, inodilators, and vasodilators on quality-of-life in advanced heart failure patients were analysed.

1. Introduction

Advanced heart failure (AdHF) is a malignant disease by nature [1]. It is characterised by a debilitating late course, with increasingly frequent hospitalisations and considerable morbidity besides the obvious mortality [2]. Heart failure affects quality of life (QoL) more profoundly than many other chronic diseases [3]. Even though QoL is a major concern, it appears that clinical management as well as research efforts do not focus sufficiently on this aspect. There is no good universal understanding of QoL in clinical practice [4]. Moreover, clinical trials often lack the assessment of relevant parameters, let alone using them as endpoints. Methods used are often subjective nonparametric measures either by patient or treating physician. In AdHF, daily variation is high and challenging for statistical analysis. Changes in echocardiographic or laboratory parameters indeed represent quantifiable outcomes, but they do not necessarily improve the daily life of the study participants, which is related to variables less easy to be quantified, such as self-care [5]. Also, QoL is by itself frequently variable in heart failure patients experience sometimes for reasons independent from the clinical conditions of the patient.

Treatment generally aims at reducing mortality, but longevity might well be an overrated goal in the management of AdHF. If the patient has to choose between prolongation of life and maintaining acceptable QoL, the choice is not always obvious. For example, some patients might decide against the implantation of an implantable cardiac defibrillator (ICD), even though they know that this choice can shorten their survival [6, 7], when sudden death is foreseen as the most desirable outcome. Also, decisions can change over time, depending on the feelings of the patients and their families. As yet, there is only little data to shed light on this trade-off.

Finally, when AdHF patients experience a decompensation and are hospitalised they often receive, on top of the optimal treatment with ACEi/ARB, β-blockers, and aldosterone-antagonist, some i.v. vasoactive treatment, i.e. inotropes, inodilators, and vasodilators. There seems to be scarce evidence on the effect of these i.v. treatments for hospitalised AdHF patients on short- or long-term QoL.

A panel of 34 experts in the field of cardiology, intensive care medicine, and cardiovascular pharmacology from 21 countries (Austria, Brazil, Colombia, Croatia, Czech Republic, Finland, Germany, Greece, Hungary, Israel, Italy, Mexico, Norway, Poland, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, and Ukraine) convened in Munich on January 23, 2015 for reviewing the existing data on QoL in patients with AdHF, and for discussing and reaching a consensus on the validity and significance of QoL assessment methods. Gaps in routine care and research, which should be addressed, were identified. Finally, published data on the effect of non-pharmacologic and pharmacologic treatments on QoL in AdHF patients were analysed.

2. Definition of QoL

QoL is not well defined in chronic heart failure and even less so in acute heart failure. None of the guidelines specify this outcome. Apparently, some aspects such as depression and social function disability, which are shown to have a significant impact on health-related QoL in patients with heart failure [8], are not taken into consideration to a satisfying degree. Other factors affecting QoL and functionality comprise persistent congestion, neurohormonal/inflammatory activation, reduced peripheral muscle blood flow/myopathy, reduced kidney function, and right ventricular dysfunction, along with severely compromised haemodynamic state, which lead to cachexia. The inflammatory activation present in heart failure has been shown to correlate with QoL [9]. Moreover, QoL decreases as New York Heart Association (NYHA) functional class worsens [10]. Finally, exercise intolerance is a key factor.

Most of the available quality-of-life scores, such as the Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the Kansas City Cardiomyopathy Questionnaire (KCCQ), are related to three major dimensions: physical, emotional, and social. Indeed, the data on available treatments commonly relate to the effects of therapy on these dimensions, but they are often rendered as the overall QoL scores without a thorough discussion of the individual domains.

3. Assessment of QoL

Besides objective surrogate measurements, various subjective methods can be used to assess the QoL in patients with heart failure, depending on whether their condition is acute or chronic (Table 1). A pilot study suggests that health-related quality-of-life measures can be reliably collected using internet-based software [11]. Data collected in this manner are valid and of comparable quality to self-reported data

Table 1
Current methods to assess the QoL in acute and chronic heart failure.

Acute heart failure
- Visual analogue scale
- Likert scale (both by patient or physician)
- Surrogate measures of dyspnoea index, BNP levels, lung function according to peak expiratory flow measures, and others.

Chronic heart failure
- Web-based possibilities to ask patients how they feel (questionnaires)
- Standard questionnaire: Minnesota living with heart failure (MLHF)
- Standard questionnaire: Kansas city cardiomyopathy questionnaire (KCCQ)
- 6 min walking test is also used as an indicator of QoL or quality of performance
- New York Heart Association functional class
- RAND-36 general health survey (computer-based, requires the patient to be able to use the system)