Rev Port Cardiol. 2020;**39(7)**:375–376

Portuguese Society of
CARDIOLOGY

Revista Portuguesa de
Cardiologia
Portuguese Journal of **Cardiology**
www.revportcardiol.org

EDITORIAL COMMENT

Health-related quality of life in heart disease

Qualidade de vida e saúde na doença cardíaca

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Over recent decades there have been tremendous advances in the treatment of patients with heart disease,[1] leading to significant increases in overall life span. As people live longer, the importance of how they live their lives has become the focus of patient-reported outcome measures, with patients ultimately having to assess whether or not a treatment has been effective.[2] There is a clear scientific and practical need to answer the following questions: What do we know about the quality of their additional life years? How do patients perceive their life after a particular procedure (e.g. heart surgery) or with a continuing treatment (e.g. device therapy)? What can we tell patients to expect from life after being treated?[3,4] Hence, population-based studies such as that by Timóteo et al. published in this issue of the *Journal*[5] are of importance to estimate patients' quality of life (QoL) in naturalistic settings.

Evaluation of existing and new therapies has traditionally focused on outcomes of disease progression, such as sudden death, survival rates, or hospital (re)admission, or, increasingly, on costs (direct and indirect). The patient's health status – symptoms, functional status or health-related QoL (HRQoL) – has only recently become the subject of research. Nevertheless, patients have always undergone assessment of symptoms and functional status. Cardiology was among the first clinical disciplines to develop a measurement of functional status, the New York Heart Association classification.[3] However, these functional status measurements have been used from the physician's point of view and were never designed to capture the point of view of the individual patient. The question is: which matters most to a patient: maximum heart rate or VO_{2max}, or the ability to perform daily activities and take part in everyday social life? QoL research aims to address the core principle that what matters is patients and their view. A basic principle of QoL research is that QoL is uniquely perceived by a person and is thus a patient's assessment of their own health and QoL that has not been interpreted by a clinician or anyone else. QoL as an outcome measure focuses on the impact of a condition and its treatment on the patient's emotional, physical and social functioning and well-being.[4]

Reliable and valid instruments for assessing patient-reported outcomes, including HRQoL, for patients with heart disease, have been successfully developed on an international basis (e.g. the MacNew Heart Disease health-related quality of life[6] and HeartQoL instruments[7]). Factors influencing patient-reported QoL have been identified[8] and QoL scores successfully predict long-term outcomes including rehospitalization and mortality,[9,10] making them one of the most meaningful clinical tools.

As well as being an accepted outcome criterion, HRQoL assessment can also change the way patients and physicians interact with each other. Doctor-patient communication is an important and complex process of building a working relationship based on trust. Patients are more confident in decisions in which they perceived more involvement or which were the products of longer consultation.[11] The integration of HRQoL assessments into routine clinical practice can change the way patients and physicians communicate with each other and improve treatment outcomes.[12,13] Assessment methods, including on paper, by telephone, or via a computer or other electronic device, are readily

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https://doi.org/10.1016/j.repc.2020.06.007

available to foster implementation in clinical practice. The choice of mode of administration may be determined by the setting in which patients complete patient-reported outcome assessments, e.g. paper-based instruments may be feasible in clinics if staff are available to hand out, collect and score questionnaires, the use of touch-screens is known to be feasible in the clinic but requires investment in hardware and software, while web-based modes of administration enables completion at home and therefore at times other than scheduled clinic visits.[14]

Despite the practical and clinical relevance of QoL research in health care, there are still scientific challenges that require further detailed research. One very basic challenge that is not fully resolved relates to the meaning and interpretation of QoL scores, in particular change scores. This is a high-priority issue, as patient-reported outcome measures are increasingly used for decisions concerning patient-centered care and policy. Changes in QoL scores can have different meanings from different perspectives, such as the societal perspective, in which differences may be small considering overall population levels, or from an institutional perspective, which focuses on the degree of change required to influence health care policies. These may very well contrast with the individual perspective, which focuses on the meaningful change of QoL for an individual. The minimal important difference (MID) is an important patient-centered concept that captures both the magnitude of improvement and the value patients place on the change. MID and minimal clinically important difference (MCID) are often used synonymously in the literature, making it more difficult to differentiate these concepts. A recent literature review revealed that the methodology to develop MIDs/MCIDs is not consistently applied and varies between anchor-based and distribution-based methods. Furthermore, most MIDs are reported as single numbers, without information about the confidence intervals around them.[15]

A second important challenge relating to interpreting change scores in QoL is the dilemma of the response-shift phenomenon.[16] Individuals actively construct meaning from their environment, and display a range of cognitive mechanisms to continually adapt to changing circumstances. Response shift refers to a change in the meaning of an individual's assessment of a construct (such as QoL) as a result of a change in their internal standards of measurement, values, or definition of the construct. These changes may result from external factors such as treatment, a change in health status or other circumstances, but also from within the individual. Three different types of response shift have been described[16]: reconceptualization (change in the definition of the target construct), recalibration (change in internal standards of measurement), and reprioritization (change in values). Repeated measurements as standard methodology in clinical trials may be affected by response shift phenomena. The variety of potential changes has important implications for the ability to reliably assess the true effects of treatments. Change in QoL scores may reflect a response shift, a true treatment effect, or a complex combination of both, and conversely, an absence of identified change over time may be masked by response shift.[17]

Summarizing, QoL is a key patient-reported outcome measure in cardiology. With valid and reliable measures readily available to assess QoL in heart disease patients, routine QoL assessment in clinical practice can easily be implemented via different feasible modes of administrations. Further efforts are needed to address the interpretation of QoL scores in cardiology, making them more meaningful for clinical routine practice.

Conflicts of interest

The author has no conflicts of interest to declare.

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