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Editorial

Is quality of life the ultimate outcome parameter?

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Over the past few years, a large amount of studies on quality of life (QOL) have been published in the *European Journal of Cardiovascular Nursing*. More specifically, from January 2011–October 2013, up to 29 empirical studies measuring QOL in a quantitative manner were published in this journal.¹⁻²⁹ A closer look at the characteristics of these studies shows that most of them were conducted in Europe ($n=14$), followed by the US ($n=8$) and Asia ($n=7$). A wide variety of patient populations were studied, including patients with heart failure ($n=12$), coronary artery disease ($n=4$), congenital heart disease ($n=3$), metabolic syndrome ($n=2$), myocardial infarction ($n=2$), pulmonary hypertension ($n=1$), atrial fibrillation ($n=1$), abdominal aortic aneurysm ($n=1$), refractory angina pectoris ($n=1$), an implantable cardioverter defibrillator ($n=1$) and patients undergoing cardiac surgery ($n=1$). Sample sizes ranged from 34²⁹ to 1109 patients.¹⁷ The vast majority of these studies ($n=20$) used a cross-sectional design.

The publications on QOL in the *European Journal of Cardiovascular Nursing* are illustrative of the attention that is being paid to patients' QOL in cardiovascular nursing research worldwide. However, one might wonder if QOL deserves this much attention. In other words, is QOL still an important factor to focus on in cardiovascular nursing research? With regard to this question, the results of a recently published longitudinal study in a large sample of adolescents with congenital heart disease can be enlightening.³⁰ This study examined how depressive symptoms, loneliness, perceived health, parental support and QOL predicted one another over time.³⁰ The investigators used cross-lagged path analysis, which is a type of structural equation modelling that allows one to uncover the direction of relationships between variables. The results showed that depressive symptoms, loneliness, perceived health and parental support predicted QOL over time, whereas QOL in itself did not predict changes in any of these previous variables.³⁰ Apparently, QOL was the ultimate outcome parameter in this sample of young patients with congenital heart disease. Thus, it is

suggested that QOL remains an important outcome measure that deserves continuing attention.

Irrespective the continuous need for research on QOL in cardiac populations, it can be questioned what kind of studies are needed to bring the body of knowledge to the next level. Most published research to date has a cross-sectional design. Such a design can explore associations between variables, but does not make it possible to examine the direction of effects between QOL and other variables of interest. In order to do so, longitudinal study designs are required. Furthermore, rigorous statistical techniques to analyse longitudinal data, such as cross-lagged path analysis, ought to be applied. This type of analysis goes beyond classical association testing and, although cross-lagged results should not be interpreted as definite proof of causation, it does allow drawing conclusions on the directionality of relationships. Interestingly, six out of the 20 aforementioned cross-sectional studies on QOL, recently published in the *European Journal of Cardiovascular Nursing*, comment on the limitations of their study design in the discussion section.^{1,5,10,20,23,26} All of these studies recognize the fact that they were unable to examine causal relationships and some of them clearly recommend longitudinal research to explore the direction of effects.

Another point of discussion is the appropriateness of the term health-related QOL.³¹ Health-related QOL has been developed to describe aspects of an individual's subjective experience that relate both directly and indirectly to health, disease, disability and impairment,³² and the effectiveness of treatment. Health-related QOL is often operationalised by assessing physical, mental/cognitive, and social functioning domains and by relying on the WHO definition of health: 'a state of complete physical, mental and social well-being and not merely absence of disease or infirmity'.³³ However, focusing on health-related QOL, investigators may substantially overestimate the impact of health-related factors and conversely, may seriously undervalue the effect of non-medical phenomena.³⁴ Furthermore,

this may suggest that assessment of QOL in healthy people or non-medical populations could be less important. Even in ill people, the distinction between overall quality of life and health-related QOL is artificial, since patients must distinguish between the part of their life influenced by health and other parts of their life not appreciably influenced by health.^{35,36} Very often, health-related QOL is used by researchers and clinicians who are actually referring to the perceived health of the patients.³⁷ Hence, the concept of health-related QOL is a subject for debate, and should therefore be used with caution or even avoided.³⁷

In conclusion, we still need to know more about the role of QOL in cardiovascular patients. Indeed, QOL not only receives the attention it deserves, research on QOL in cardiac populations merits a need to be strengthened and expanded. In order to expand our knowledge on this topic and, hence, to continuously improve our care for patients, the focus of cardiovascular nursing research should shift from cross-sectional studies to longitudinal research. Furthermore, a sound conceptual basis for QOL is needed. This will help us to get a better understanding of the dynamics of QOL as the ultimate outcome parameter.

Conflict of interest

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