Quality of life research, it's only the beginning

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The two papers by Van Geldorp et al., published in this first number of the Netherlands Heart Journal 2013, focus on quality of life (QoL), and specifically that of patients with aortic valve stenosis. [1, 2]

Since the end of the 1990s, QoL has gained more importance in medicine, social sciences and health services. In medical decision-making in healthcare, costs and financial aspects have become very important. The major question is not only if it is reasonable to spend money for a specific treatment for only a small number of patients, or which percentage of treated patients will survive for a longer period, but also if a treatment results in an improved QoL. During recent years even health insurance companies focus on hard QoL data as endpoints. Post-treatment life expectancy of patients with a cardiac disease has increased. However, this increased life expectancy does not imply an improved QoL. It is therefore not surprising that also in the literature we see QoL more and more as one of the studied endpoints in clinical studies [3].

Due to the increasing age of the patients, also cardiologists and cardiac surgeons are regularly confronted with questions concerning expected QoL after treatment. Most studies focus on this aspect. At that point you can imagine that these studies are comparable with survival studies. However, in contrast to survival studies, which start with a number of living patients and compare that with the number of patients still alive at a certain moment, most QoL studies do not start with preoperative QoL data. Moreover, patients are selected at a certain moment postoperatively or post-treatment and invited to participate in a QoL study, and to complete a QoL questionnaire. For the study, only those patients who meet the study criteria—complete QoL information—are

included in the evaluation. If we compare this again with a simple survival analysis, this means that, at a certain moment postoperatively, post-treatment, a number of surviving patients would be identified and a conclusion about survival made on only these patients. What is also misleading is that a lot of these studies pretend to have a ‘follow-up’ period. Because QoL information is only provided at one moment, these studies do not supply information on how QoL has changed post-treatment [3].

If studies start with preoperative QoL assessment and go on to compare this with a postoperative QoL registration we see the problem of a high dropout of patients [3]. This dropout is not the same as ‘lost for follow-up’, but it means that patients who could be included in the study are not included because of the lack of QoL information. It already starts with patients not, or not completely, replying to the preoperative QoL questionnaire. Also at the end of the study, a number of patients do not reply, or do not fully complete the QoL questionnaire. Of course, patients who die during the follow-up will never reply to the QoL questionnaire. Because only patients with both complete preoperative and complete postoperative QoL information are included in the analysis, it is important that studies also describe and discuss information, demographics, and risks about the dropouts, before a conclusion is made for the total population. Several studies parry this problem, by simply ignoring the dropouts [3]. Recently at the meeting ‘Meetbaar beter’ (12 October 2012, Sint-Michielsgestel, the Netherlands, www.meetbaarbeter.com), where two Dutch heart centres presented their data, the attentive listener was also confronted with this dropout problem. Data of QoL registration one-year post-cardiac surgery were presented (oral communication). There was a response of only 28 % in contrast with the more than 99 % survival information. One reason for dropout is certainly the QoL questionnaires themselves. Most of these questionnaires contain a lot of questions, and people have to take time to complete all these questions. Certainly for older people, this is a lot of work and during a longer follow-up

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there is always a decrease of response. With the years, people are not so motivated to complete these mostly extensive questionnaires [4]. Probably, as Van Geldorp remarks, the use of the validated EuroQol survey [1], primarily designed for self-completion by respondents, cognitively simple, and taking only a few minutes to complete, could be an option to decrease the number of dropouts due to lack of QoL information, certainly when it is the intention to register these data over several years.

Van Geldorp et al. [1] it's true, focused not on QoL of patients before and after aortic valve replacement, but on the quality of life when the decision to operate or not is yet to be made. This is a new dimension in this kind of research and a very important one. But also here, the authors are confronted with a high number of dropouts. Of the 459 patients with a severe aortic stenosis who could be included in their study, 185 (40 %) declined participation. Important is that the reasons to refuse to participate were most often high age and severe disability, variables probably influencing the QoL of these patients. It is a pity that these data were not shown and not discussed in the study. What is remarkable is that Van Geldorp et al. demonstrated that the scores of the SF-36v2™ correspond well with the severity of symptoms according to New York Heart Association (NYHA) classification [1]. This is in contrast with Rumsfeld who indicated that in patients with coronary artery bypass grafting, preoperatively the correlation between NYHA class and QoL is low [5]. However, this proves again how dangerous it is to generalise the results of a specific population for the whole population in this kind of research. Also in the second report, the authors critically reflect on the underestimation of QoL impairment in their total patient population because the dropouts are most likely those with a low quality of life [2]. This is an important

remark because it means that information about QoL mostly overestimates the reality.

In an era where evidence-based medicine is of such great importance, the lack of major and well-organised clinical studies dealing with indication for cardiac surgery, invasive treatment or conservative treatment of cardiac diseases, and quality of life is incomprehensible. Medical doctors need information on the impact of treatments, interventions and cardiac operations and on the resulting quality of life, not only to justify their decisions but also to inform their patients about the pros and cons of their decision. It is, however, important that people realise that quality of life research is still in its infancy, and critical reflections about the results and conclusions, as done by Van Geldorp et al., are at this moment as important as the conclusions [1, 2].

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