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Editorial

Quality of life evaluation in cardiovascular disease: a role for the European Society of Cardiology?

Hannah M. McGee[a], Neil Oldridge[b] and Irene M. Hellemans[c]

[a]Health Services Research Centre, Department of Psychology, Royal College of Surgeons in Ireland, Dublin, Ireland, [b]School of Health and Rehabilitation Sciences, Indiana University and College of Health Sciences, University of Wisconsin, Milwaukee, Wisconsin, USA and [c]Department of Health Sciences, Free University, Amsterdam, The Netherlands.

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Quality of life, or more precisely health-related quality of life (HRQL), is a concept cited increasingly often as an outcome measure in cardiovascular conditions. The mission statement, no less, of the European Society of Cardiology (ESC), sets HRQL as its ultimate goal:

> 'To improve the quality of life of the European population by reducing the impact of cardiovascular disease.'

Similarly, the World Health Organization's widely cited definition of cardiac rehabilitation identifies it as a mechanism to deliver secondary prevention and to improve patient HRQL. Since the year 2000, there were 2004 papers in Medline combining the keywords 'cardiovascular' or 'cardiac' and 'quality of life'. Given the prominence of the concept, it would be reasonable to assume that there are clear and agreed definitions and measurement criteria for evaluating HRQL, or at least mechanisms to achieve this, in the cardiovascular setting. This is not the case. HRQL, let alone the more generic concept of quality of life, is seldom explicitly defined, but is nonetheless measured in a myriad of ways with little consistency and thus an inability to build a cumulative comparative evidence base over time. To borrow an analogy used elsewhere in commentary on HRQL, a virtual Tower of Babel exists in relation to findings from HRQL studies in cardiovascular disease.

But why should it be the role of the ESC, rather than individual researchers, to build consensus in this field? We argue that the opportunity to unite researchers and research efforts by encouraging a common 'language' for research studies is an important function of the ESC and not easily achievable otherwise. To take a parallel, a European Union initiative to develop Cardiac Audit and Registration Standards (CARDS) was undertaken during the Irish Presidency of the European Union in 2004 [1]. This process, developed in cooperation with the ESC, means that for the first time there is agreement to collect a minimum dataset of information on three acute cardiovascular scenarios: acute coronary syndrome; percutaneous coronary angioplasty; and electrophysiology. A parallel cardiac rehabilitation module has been inspired by this work [2]. The benefit to the cardiovascular community of these agreed standards is enormous and will probably only be realized a decade from now. The achievement was not possible without the ESC being seen to have legitimacy as an umbrella organization by all of the relevant players. The cooperation achieved also means that activities such as the Euro Heart Survey can hope over time to obtain data from individual centres within and across countries that is already recorded in a common format.

We also argue that the field of cardiovascular medicine must be able to make its case for healthcare resources in an evolving environment of comparative benefit for investment. Professionals working in other major chronic conditions, notably oncology and rheumatology, are well advanced in building a common international research framework on HRQL effects of their conditions and healthcare interventions. This cumulative evidence can be used effectively to make the case for resources for health interventions in these specialities. In rheumatology, the Outcome Measures for Arthritis Clinical Trials (OMERACT) has achieved consensus on HRQL instruments to promote across studies such that studies can directly contribute to building a collective body of evidence [3]. A first decision to advise using

Correspondence to Hannah M. McGee, Health Services Research Centre, Department of Psychology, Royal College of Surgeons in Ireland, Dublin, Ireland.
E-mail: hmcgee@rcsi.ie

disease-specific instruments because of their responsiveness has since been tailored with strategic advice also to use generic measures, so that conditions or interventions in rheumatology can be compared with other diseases or the general population to demonstrate problems caused by arthritis and the benefits of interventions. In oncology, the European Organization for Research and Treatment in Cancer (EORTC) has a similar goal. It has developed a core cancer HRQL scale with specialist modules for different types of cancer [4]. It also promotes the use of generic health status instruments to demonstrate problems and benefits from conditions and treatments, respectively. It has the added attraction as a model for the ESC in that it facilitates research studies across European borders and languages, thus removing language as a barrier to large clinical trials in Europe.

Our encouragement of similar strategies within the ESC does not come from a neutral stance. We are involved in an ESC supported research project, collaborating with the European Health Psychology Society, called Euro Cardio-QoL. The EuroCardioQoL project is designed to develop a single reliable and valid core coronary heart disease-specific HRQL questionnaire, to be called the HeartQoL, and to be eventually available in 13 different European languages. This can allow comparison of outcomes with the same, or different, treatments among pure or mixed populations of patients with myocardial infarction, angina pectoris, or heart failure [5]. It is expected that the instrument will be available for use in 2007. This project is not necessarily the only appropriate approach. It does, however, address the challenges of measuring HRQL across differing cardiac populations and the need to be able to assess outcomes across languages in Europe. The major advantage of having a single core heart disease HRQL instrument is to optimize the efficiency of inter- and intra-study comparisons by being able to make both across-diagnosis, within-treatment comparisons, and also across-treatment, within-diagnosis comparisons with the same instrument.

Developing consensus with regard to core-specific HRQL measurement instruments for use across cardiovascular conditions and interventions has great potential value. This would facilitate the accumulation of expertise, and allow the values and profiles emerging to become interpretable in the same way that values on other parameters were developed and have become familiar over time, e.g. hypertension and cholesterol.

In sum, the cardiovascular research community needs to optimize the considerable energy spent in HRQL assessment by coordinating this work. This would help create a consensus that will allow a comprehensive and cumulative body of evidence to emerge on this most important of outcomes for patients and the community more generally. The Board of the ESC, perhaps through the newly developing Association of Cardiovascular Prevention and Rehabilitation, seems particularly well placed to lead such an initiative.

References

1 Shelley E, Ryden L. Promoting heart health – a European consensus. *Eur J Cardiovasc Prevent Rehabil* 2004; **11**:85–86.
2 ESC Working Group on Cardiac Rehabilitation and Exercise Physiology. Cardiac Rehabilitation Audit Standards. Developing consensus on a core dataset for Europe. Unpublished report. Available from: hmcgee@rcsi.ie. 2004.
3 Brooks P, Hochberg M. Outcome measures and classification criteria for the rheumatic diseases. A compilation of data from OMERACT (Outcome Measures for Arthritis Clinical Trials), ILAR (International League of Associations for Rheumatology), regional leagues and other groups. *Rheumatology* 2001; **40**:896–906.
4 Sprangers MA, Cull A, Groenvold M, Bjordal K, Blazeby J, Aaronson NK. The European Organization for Research and Treatment of Cancer approach to developing questionnaire modules: an update and overview. EORTC Quality of Life Study Group. *Qual Life Res* 1998; **7**:291–300.
5 Oldridge N, Saner H, McGee HM, for the EuroCardioQoL Study Investigators. The Euro Cardio-QoL Project. An international study to develop a core heart disease health-related quality of life questionnaire, the HeartQoL. *Eur J Cardiovasc Prevent Rehabil* 2005; **12**:87–94.