

Research Letter

The HeartQoL study. An International Project to Develop a Core Heart Disease Health-Related Quality of Life Questionnaire

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Introduction: 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. It has been measured in a myriad of ways with little consistency and thus an inability to build a cumulative comparative evidence base over time. Therefore, the European Society of Cardiology's Working Group in Cardiac Rehabilitation and Exercise Physiology (since 2004 changed to the newly created European Association for Cardiovascular Prevention and Rehabilitation) have developed a project called EuroCardioQoL to establish a single reliable and valid core coronary heart disease specific HRQL questionnaire, to be called the HeartQL, and to be eventually available in 13 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, and/or heart failure. The project is led by a multi-disciplinary team including an exercise physiologist (NO), a cardiologist (HS) and a health psychologist (HM). The EHPS is a named partner in this project through input of a number of its members on the Steering Group: David Hevey (Ireland), Derek Johnston (Scotland), Juhani Julkunen (Finland), Maria Kopp (Hungary) and Therese van Elderen (Netherlands).

Methods: The study protocol involves collecting data in a total of 15 European countries with 40 sites. The questionnaires to be used are each available in Dutch, English, Finnish, Flemish, French, German, Italian, Lithuanian, Norwegian, Portuguese, Russian, Spanish, and Swedish. Each of the 40 sites will continue to collect data until 35 patients with each diagnosis are accrued, resulting in a total of 4,200 patients across 13 languages. Patients with myocardial infarction (MI), angina, or heart failure are being recruited. They complete self-report questionnaires once with 25% of patients completing further information for test-retest purposes. The selected questionnaires are previously validated specific HRQL questionnaires and other patient-centered measures:

Heart Disease Specific HRQL questionnaires

The primary outcome of the study will be the development of a core heart disease HRQL instrument for use in research and hopefully also suitable for use in clinical practice. The core heart disease HRQL instrument [and modules if necessary] will be developed from the responses to reliable, valid and responsive specific HRQL instruments previously used as outcome measures in randomized controlled trials of intervention in patients with MI, angina, and heart failure. Instruments were chosen on the basis of these criteria and also that they were available in each of the proposed languages groups:

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- The MacNew Heart Disease HRQL questionnaire (27 items in three domains: physical [8 items], emotional [11 items], and social function [8 items]).
- The Seattle Angina Questionnaire [SAQ] (19 items in three domains: physical and symptoms [12 items], treatment satisfaction [4 items], and disease perception [3 items]).
- The Minnesota Living With Heart Failure Questionnaire [LHF] (21 items in three domains: physical and symptoms [11 items], psychological [seven items], and socioeconomic [3 items]).
- Other patient-centered psychosocial questionnaires to be used for psychometric validation: Hospital Anxiety and Depression Scale; Global Mood Scale; Type D Scale; and Medical Outcome Study Health Survey [SF-36].

Further details on the protocol are available (Oldridge, Saner & McGee, et al., 2005).

Discussion: This study will use three existing reliable and valid heart disease specific HRQL questionnaires, each designed for use in one of the three primary CHD diagnoses, i.e., MI, angina, and heart failure, as the basis from which to develop a single heart disease core HRQL instrument that can be used in each of the three CHD diagnoses. Many patients will experience more than one of these conditions either in parallel or consecutively and many treatments cover more than one category of these patients. Thus a single measure can give a more meaningful evaluation of patient status and of treatment efficacy (McGee, Oldridge & Hellemans, 2005). Strengths of the study include the large number of patients and the range of languages involved. The potential of this project is evidenced by the interest among investigators from the 40 different sites in 15 different countries who have essentially volunteered their time and effort to conduct this study. The project is currently underway in all sites. It is hoped that data collection will be completed in 2006 with first reports on a core instrument expected in 2007. It is hoped this instrument will facilitate cross-national and cross-language studies in Europe and elsewhere.

Acknowledgements

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References

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