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REQUIREMENTS FOR QUALITY-OF-LIFE REPORTS

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Editorial

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Quality of life is an increasingly popular concept in the field of nursing and medicine. Since the 1970s, the number of articles on quality of life appearing in the biomedical literature has increased exponentially (1). Also in the European Journal of Cardiovascular Nursing, many quality-of-life reports are published. In 2008 and 2009 alone, 15 studies in which quality of life was measured, were published in the journal (2-16), corresponding with 17% of all research papers.

However, quality of life is a concept with a lot of challenges (17). There is still no consensus regarding the conceptualization, operational definition, and measurement of quality of life (18). The lack of a uniform definition for quality of life contributes to its conceptual vagueness and obscurity (18). Evidently, interpretation of results from quality-of-life studies is complicated when investigators do not use a consistent conceptual basis to define quality of life, or if they do not define quality of life at all (18).

This problem was already in 1994 recognized by Gill and Feinstein, when they assessed the quality of quality-of-life measurements in different patient populations (19). They developed 10 criteria (Table 1) that were subsequently used in their evaluation of 75 randomly selected quality-of-life studies. Gill and Feinstein concluded that most quality-of-life studies required methodological improvement because they “aimed at the wrong target” (19). Ten years later, the same criteria were used in a study on the caliber of quality-of-life assessments in children, adolescents and adults with congenital heart disease (18). The latter article concluded that the poor conceptual and methodological basis used in these studies implies that many results of quality-of-life studies in patients with congenital heart disease were inconclusive. The authors, therefore, plead for more conceptual and methodological rigor with respect to future quality-of-life studies (18).

Investigators who are planning a study in which quality of life will be measured, can rely on the Gill & Feinstein criteria to ensure that the conceptual and methodological quality of their study is good. However, we could propose some additional elements that should be addressed to improve

the quality of quality-of-life studies. First, investigators should make sure that they are measuring quality of life and not health status. There is increasing evidence that quality of life and health status are two related, though distinct concepts (17). Hence, it is conceptually incorrect to use these terms interchangeably. Moreover, it is not sufficient to dodge this discussion by just applying the term health-related quality of life. Second, investigators should make sure that they are measuring indicators of quality of life, and not merely determinants of quality of life. Indicators are events or conditions that typically characterize a specific situation. Determinants, on the other hand, are defined as elements that determine the nature of something (Merriam-Webster online: <http://www.merriam-webster.com/dictionary/>), and can therefore be considered as external factors that affect a phenomenon. The distinction between indicators and determinants is crucial for conceptualising and measuring quality of life (1). A study that is only measuring determinants of quality of life, such as health status, symptoms, mood, physical functioning, etc, cannot be considered to be a quality-of-life study, because quality of life itself is not addressed. On the other hand, instruments such as a Linear Analogue Scale or the Satisfaction with Life Scale can be used as indicators for quality of life (20).

To improve the caliber of quality-of-life studies published we propose some minimal requirements for quality-of-life reports

1. **Authors are required to provide the definition of quality of life that they have used in their study.** This is imperative to make sure that readers understand what the authors mean with the term quality of life. In addition, it allows reviewers and readers to check whether quality of life is not interchanged with other related concepts, such as health status or functional status.
2. **Authors are required to explicitly state the domains that they have measured as components of quality of life.** Quality of life is typically considered to be a

multidimensional or multifactorial construct. Hence, it comprises multiple domains. The choice of quality-of-life instrument(s) basically relies on the components included in the instrument(s). To determine whether the selected measurement was suitable to assess the desired target, authors should explicitly state which domains they consider to be significant elements of quality of life (19).

3. Authors are required to give the reason(s) for choosing the instruments they used.

Valid assessments require that the instruments used are suitable for the intended task. Since numerous quality-of-life instruments exist, investigators need to state their reasons for choosing to use a particular instrument or instruments to assess quality of life (19). These reasons should ensure that quality of life is measured appropriately according to their intended goals. Just because an instrument has good psychometric properties or is widely used does not mean suitable reasons were considered for its use.

4. Authors are required to state whether they measured overall quality of life or health-related quality of life.

Health care professionals are predominantly interested in health-related factors to be components of patients' quality of life. However, a holistic approach implies that also non-medical phenomena emerge. Consequently, a distinction between overall and health-related quality of life should be made clear in quality-of-life papers (19).

5. Authors are required to explicitly state the indicators and determinants of quality of life that they have measured in their study.

Investigators need to stipulate how they have measured quality of life itself (by its indicators), and how they have assessed influencing factors (by its determinants). A clear distinction between indicators and determinants of quality of life is imperative.

Authors who are submitting a quality-of-life report to the European Journal of Cardiovascular Nursing are invited to use these requirements. By doing so, we can improve the conceptual and methodological rigor of quality-of-life studies and expand the knowledge base in this important field of research..

Reference List

- (1) Moons P, Budts W, De Geest S. Critique on the conceptualisation of quality of life: a review and evaluation of different conceptual approaches. *Int J Nurs Stud* 2006; 43(7):891-901.
- (2) Koivunen K, Lukkarinen H. One-year prospective health-related quality-of-life outcomes in patients treated with conservative method, endovascular treatment or open surgery for symptomatic lower limb atherosclerotic disease. *Eur J Cardiovasc Nurs* 2008; 7(3):247-256.
- (3) Patel H, Ekman I, Spertus JA, Wasserman SM, Persson LO. Psychometric properties of a Swedish version of the Kansas City Cardiomyopathy Questionnaire in a Chronic Heart Failure population. *Eur J Cardiovasc Nurs* 2008; 7(3):214-221.
- (4) Lee GA. Patients reported health-related quality of life five years post coronary artery bypass graft surgery--a methodological study. *Eur J Cardiovasc Nurs* 2008; 7(1):67-72.
- (5) Johansson P, Brostrom A, Dahlstrom U, Alehagen U. Global perceived health and health-related quality of life in elderly primary care patients with symptoms of heart failure. *Eur J Cardiovasc Nurs* 2008; 7(4):269-276.
- (6) Moons P, Van Deyk K, Marquet K, De Bleser L, De Geest S, Budts W. Profile of adults with congenital heart disease having a good, moderate, or poor quality of life: a cluster analytic study. *Eur J Cardiovasc Nurs* 2009; 8(2):151-157.
- (7) Merkouris A, Apostolakis E, Pistolas D, Papagiannaki V, Diakomopoulou E, Patiraki E. Quality of life after coronary artery bypass graft surgery in the elderly. *Eur J Cardiovasc Nurs* 2009; 8(1):74-81.
- (8) Back M, Wennerblom B, Wittboldt S, Cider A. Effects of high frequency exercise in patients before and after elective percutaneous coronary intervention. *Eur J Cardiovasc Nurs* 2008; 7(4):307-313.

- (9) Witham MD, Daykin AR, McMurdo ME. Pilot study of an exercise intervention suitable for older heart failure patients with left ventricular systolic dysfunction. *Eur J Cardiovasc Nurs* 2008; 7(4):303-306.
- (10) Broddadottir H, Jensen L, Norris C, Graham M. Health-related quality of life in women with coronary artery disease. *Eur J Cardiovasc Nurs* 2009; 8(1):18-25.
- (11) Austin J, Williams WR, Hutchison S. Multidisciplinary management of elderly patients with chronic heart failure: five year outcome measures in death and survivor groups. *Eur J Cardiovasc Nurs* 2009; 8(1):34-39.
- (12) McKee G. Are there meaningful longitudinal changes in health related quality of life--SF36, in cardiac rehabilitation patients? *Eur J Cardiovasc Nurs* 2009; 8(1):40-47.
- (13) Miche E, Roelleke E, Zoller B, Wirtz U, Schneider M, Huerst M et al. A longitudinal study of quality of life in patients with chronic heart failure following an exercise training program. *Eur J Cardiovasc Nurs* 2009; 8(4):281-287.
- (14) Sawatzky JA, Naimark BJ. The coronary artery bypass graft surgery trajectory: Gender differences revisited. *Eur J Cardiovasc Nurs* 2009; 8(4):302-308.
- (15) Frisman GH, Kristenson M. Psychosocial status and health related quality of life in relation to the metabolic syndrome in a Swedish middle-aged population. *Eur J Cardiovasc Nurs* 2009; 8(3):207-215.
- (16) Evangelista LS, Sackett E, Dracup K. Pain and heart failure: unrecognized and untreated. *Eur J Cardiovasc Nurs* 2009; 8(3):169-173.
- (17) Moons P. Why call it health-related quality of life when you mean perceived health status? *Eur J Cardiovasc Nurs* 2004; 3(4):275-277.

- (18) Moons P, Van Deyk K, Budts W, De Geest S. Caliber of quality-of-life assessments in congenital heart disease: a plea for more conceptual and methodological rigor. Arch Pediatr Adolesc Med 2004; 158(11):1062-1069.
- (19) Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. JAMA 1994; 272(8):619-626.
- (20) Moons P, Van Deyk K, De Bleser L, Marquet K, Raes E, De Geest S et al. Quality of life and health status in adults with congenital heart disease: A direct comparison with healthy counterparts. Eur J Cardiovasc Prev Rehabil 2006; 13:407-413.

Table 1: Criteria appraising the caliber of quality-of-life studies as developed by Gill & Feinstein

(19)

Criteria
1. Did the investigators give a definition of quality of life?
2. Did they state the domains they will measure as components of quality of life?
3. Did the investigators give reasons for choosing the instruments they used?
4. Did the investigators aggregate the results from multiple items, domains, or instruments into a single composite score for quality of life?
5. Were patients asked to give their own global rating for quality of life?
6. Was overall quality of life distinguished from health-related quality of life?
7. Were patients invited to supplement the items listed in the instruments offered by the investigators that they considered relevant for their quality of life?
8. If so, were these supplemental items incorporated into the final rating?
9. Were patients asked to indicate which items (either specified by the investigator or added by the patients) were personally important to them.
10. If so, were these importance ratings incorporated into the final rating?