Quality of life of patients and health care professionals

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Quality of life is a concept that appeared in the scientific literature in the early seventies of the previous century. The concept was introduced by oncologists who were confronted with the fact that medical treatment in terminal patients was very detrimental for their psychosocial functioning while the treatment did not significantly change their life expectancy. From that time dates the dilemma in palliative care: should we add by medical treatment years (months or weeks) to life or life to the years (months or weeks)?

While the initiative of these medical doctors was thus very noble and soon led to an enormous increase in publications on quality of life, the lack of a theoretical background created however an undesirable diversity in the use of the term and as a consequence, in the way quality of life was measured. Quality of life can indeed be considered as one of the broadest 'garbage' concepts in the psychosocial literature. Marie-Christine Taillefer and her colleagues (2003) were among the first to illustrate the wild growth of the concept in an excellent review on health-related quality of life models. They identified over 50 different definitions of quality of life and tried to categorize these different concepts into the following conceptual or theoretical frameworks : (a) happiness ; (b) well-being ; (c) satisfaction ; (d) performance ; (e) functioning ; (f) goal attainment ; (g) need satisfaction ; (h) health and (i) none of these. It is revealing that a low inter-rater reliability was found for about half of these categories, due to the fact that most authors did not give a clear definition, while about a quarter did not define the concept at all. This led to a myriad of quality of life instruments that, in contrast to e.g. depression or anxiety measures, are constructed on ad hoc basis with little concern for their psychometric properties. To make things worse, while most efforts were initially devoted to the development of general health related quality of life scales, including different aspects or categories of quality of life, the development of disease specific scales increased the specificity but also the diversity of the measures leading e.g. to subscales measuring pain, discomfort, worry, financial problems, positive feelings, communicative aspects, spiritual needs, fatigue and other disease specific symptoms.

In addition, the pragmatic attitude towards the development of quality of life measures also led to another controversy: many medical doctors use health status or functional measures to determine the quality of life of their patients that may measure health perceptions, but not necessarily quality of life. According to Moons and colleagues (2006) quality of life is indeed the result of a subjective evaluation of own life conditions and not the objective or external perception of these conditions. Needless to say that the discipline of psychology can contribute importantly to: (a) provide a theoretical base for the concept and the development of quality of life measures and (b) increase the psychometric properties of the measures.

As the review by Taillefer and colleagues (2003) showed, many psychological models can

provide a relevant theoretical background for a better understanding of quality of life. Among these, self-regulation models are a good candidate to clarify what is and what contributes to quality of life. Self-regulation can be defined as a goal-guidance process, while goals can be described as thoughts about or mental representations of desired outcomes or states. Goals have content and provide direction for our behavior (Maes & Karoly, 2005). Within this framework quality of life can be defined as the degree to which the attainment of important personal life goals is facilitated, unaffected or disturbed by a person's present condition or disease. To explore this, we conducted a study in 160 myocardial infarction (MI) patients shortly after hospitalization showing that the most powerful predictor of quality of life, anxiety and depression was personal goal disturbance as a result of their cardiac event (Boersma, Maes & Joekes, 2005). A follow-up study with 113 MI patients showed that personal goal disturbance after the event was also the most important predictor of quality of life four months later, even when controlling for demographics, disease severity, disease related coping and social support (Boersma, Maes & Van Elderen, 2005). The identification of disturbed personal goals as a consequence of a disease provides a unique opportunity for targeted interventions to increase quality of life in patients suffering from chronic diseases, since it allows to explore with the patient how important but disturbed goals can still be attained or to facilitate acceptance of the unattainability of certain goals by refocusing on other, attainable goals (Maes & Karoly, 2005). This process could also be defined as a guided response shift or in other words a change in internal standards or values (reordering the personal goal hierarchy) over time that so frequently occurs in patients suffering from a chronic condition over time (Schwartz and Sprangers, 1999).

This intervention perspective is very important since a main characteristic of many health related quality of life measures is that they provide insight in the current status, functioning or wellbeing of patients, but do not have a clear diagnostic value in view of interventions. Quality of life is indeed rather seen as a consequence of a (physical or psychological) condition or disease, than as a condition itself. As a consequence, in contrast to e.g. depression or anxiety measures, quality of life measures do not provide us with clear subclinical or clinical cut-off scores that are a good indicator for subsequent psychological interventions. In addition, conventional HRQOL questionnaires are frequently used to assess the effect of a psychological intervention in patients suffering from a chronic disease but mostly fail to show an effect (see e.g. Baraniak & Sheffield, 2011 ; Van Malderen et al 2013). While there may be many reasons for this, such as the lack of specificity of some, especially general, quality of life questionnaires, many instruments are apparently only relevant to assess patients during a specific disease stage or unable to measure changes over a longer period of time. In a follow-up study that we conducted with 1654 cardiac rehabilitation patients with the MacNew, a specific quality of life questionnaire that is widely used in patients suffering from coronary heart disease, we showed e.g. that the MacNew differentiated well at the start of cardiac rehabilitation and was responsive enough to capture beneficial changes during cardiac rehabilitation, but lost its discriminative power at the end of cardiac rehabilitation because of ceiling effects (Maes et al. 2008). Also for this reason, anxiety and depression measures should complement the assessment of quality of life over time.

Quality of life of health professionals is equally important. Publications targeting quality of working life use a range of indicators that is

almost as wide as the range for patient quality of life. Examples are work involvement, intrinsic job motivation, higher order need strength, perceived intrinsic job characteristics, job satisfaction, life satisfaction, happiness and lack of job stress, role conflict or turnover intention. This shows, as was the case for the origins of health related quality of life of patients, that many publications lack a coherent theoretical background. Such a background can e.g. be found in the Job-Demand-Social Support or JDCS model or the more recent Job Demand-Resources model. According to the JDCS model, high job demands (workload and time pressure) increase strain, while high job control (skill discretion and decision authority) and a high social support (from the boss or colleagues) diminish strain. The most detrimental work situation is characterized by high demands, low control and low social support and proves to induce many adverse physical and psychological consequences, including a low quality of working life as shown by high stress, eventually leading to burnout as well as low job satisfaction and work engagement and/or a high turnover intention (for reviews see: Van der Doef & Maes, 1998 and 1999a). As the model had been criticized for its simplicity and thus the neglect of other important determinants we conducted a literature review that contributed to the construction of the Leiden Quality of Work Questionnaire (Van der Doef & Maes, 1999b) measuring next to the JDCS dimensions also role ambiguity, physical exertion, hazardous exposure and job insecurity as relevant predictors of wellness at the worksite. While several other general questionnaires distinguished comparable predictors, we soon discovered that general quality of work questionnaires lacked the specificity to adequately unravel the job and environmental characteristics of a specific job. For this reason we developed a specific questionnaire for teachers that proved to explain up to 20% more

variance in relevant outcomes than a general scale (Van der Doef & Maes, 2002).

The teacher quality of work scale was soon followed by the Leiden Quality of Work Questionnaire Health Care (LQWQ-H), with specific questionnaires for medical doctors, nurses, laboratory and administrative personnel. The LQWQ-H measures JDCS variables and other job characteristics, but also organizational and environmental conditions based on the TRIPOD model (Akerboom & Maes, 2006). The instrument consists of 12 subscales measuring quality of work life and one scale measuring an outcome: job satisfaction. The subscales are: work and time demands, physical demands, skill discretion, decision authority, social support supervisor, social support colleagues, nurse-doctor collaboration, personnel resources, material resources, reward, work agreement and communication. Many studies have since been carried out with the LQWQ-H in populations of nurses, medical doctors and other health care professionals that confirmed its predictive power in relation to job satisfaction, job engagement, turnover intention, distress, somatic complaints and burnout (e.g. Gelsema et al, 2006; Adriaenssens et al, 2011; Pisanti, 2012). In more recent research carried out at Leiden, self-regulation constructs such as regulatory focus and personal goal facilitation proved to explain additional variance in these outcomes (e.g. Gelsema, 2007 ; Pisanti, 2012 ; Koelewijn, 2013).

It is obvious that the diagnosis of the workplace in terms of wellness risks based on instruments like the LQWQ can form a solid base for interventions. As a consequence, in the last 25 years five large worksite health promotion (WHP) projects were developed and evaluated at Leiden university. Among these are the Brabantia project, that got a lot of international attention since it was one of the first WHP projects that not only focused on lifestyle

changes and related biomedical risk factors but also on changing wellness risks. The project was especially effective in increasing job control and decreasing absenteeism in factory workers (Maes et al, 1998). More recent comparable WHP projects carried out at Leiden University Medical Center (LUMC) and the Work Without Worry (WWW) project, that aimed to improve work conditions for employees at health care centers for disabled people, also showed that a targeted intervention can have beneficial effects on relevant targets and outcomes (Verhoeven et al., 2005 ; Koelewijn, 2013).

These interventions are not only important from a quality of work life or health perspective, but also from a consumer or patient perspective since work conditions are also determinants of quality of care and patient safety (Gershon et al, 2007).

Summarizing, one could state that the relevance of the concept of quality of (working) life can be increased by a sound theoretical background and the development of valid and reliable measures that allow for an adequate diagnosis of important determinants, leading to subsequent, targeted interventions. ■

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