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GUEST EDITORIAL

Measure development and assessing outcomes in palliative care: Always look on the bright side of life…

In recent years, there has been considerable output in the literature concerning the development of scales that are meant to capture, assess, and quantify subjective outcomes in palliative care and at the end of life. Several papers in the current special issue of *Palliative & Supportive Care* on "Measurement Development in Palliative and Supportive Care" are examples of such. The importance of these endeavors for palliative care is crucial, as the main outcome of palliative care as defined by the WHO—quality of life—is among the most subjective outcomes imaginable. Indeed, there has been a longstanding controversy about whether such a construct might be measurable by any means. The main arguments against assessing quality of life concern:

1. its inherent subjectivity, which would render such a construct all but impossible to quantify;
2. its irreducible individuality, which would make interindividual or group comparisons meaningless; and
3. the danger of a "slippery slope" when imputing a definite "value"—by whatever means—to the quality of life of an individual or group of individuals in the context of a disease.

The latter argument is not to be taken lightly. Nazi propaganda once justified their program of mass murder of handicapped persons using a similar line of reasoning: when the quality of life of an individual falls below zero, ending his life becomes an act of mercy. Nowadays, the widespread methodology based on so-called "quality-adjusted life years" (QALYs) allocates financial resources in healthcare systems based on quality-of-life assumptions that tend to discriminate sick people when compared to healthy ones. Therefore, utmost care must be taken when developing scales that aim to quantify such sensitive items as quality of life or meaning in life.

Several pitfalls arise. A major one is the danger of imposing predefined views and concepts on what constitutes a "good" quality of life based on a researcher's own assumptions. This has led to the development of several questionnaires that only offer a partial, often culturally biased, set of options for respondents to choose from.

A particularly dangerous pitfall is the misunderstanding of health status as a surrogate measure for quality of life. This has led to the erroneous concept of the so-called "health-related" quality of life. In the wake of this development, several scales have undergone an interesting change in terms of how they are perceived. For example, the Short Form–36 (SF–36) and the Sickness Impact Profile (SIP) have been utilized in hundreds of clinical trials as purported "quality-of-life" measures, but in the original papers describing the instruments and their validation, the term "quality of life" never even appears: these scales were developed as health-status measures. Since palliative care research has repeatedly shown that individual quality of life does not correlate with health status (see, e.g., Neudert et al., 2004), the usage of these scales as quality-of-life measures can be deemed improper.

An interesting example of this dichotomy can be found in one of the most widely used scales, the European Organization for Research and Treatment of Cancer QLQ–C30 (EORTC–QLQ–C30). This health-related quality-of-life scale, designed for use in cancer patients, consists of 30 questions. The first 29 are mainly concerned with different aspects of health status and are summed up in question 29: "How would you rate your overall *health* during the past week?" Interestingly, question 30 reads: "How would you rate your overall *quality of life* during the past week?" It looks as though its developers at the last moment recognized that these are two fundamentally different constructs.

A major development in quality-of-life assessment came with the introduction of patient-generated instruments, so-called "idiographic" scales (as opposed to the classical fixed questionnaires, which are termed "nomothetic"). One of the pioneers of this development, Dr. Ciarán O'Boyle of Dublin, started his work on a seemingly trivial but in fact all-important assumption: "Quality of life is whatever the patient says it is." This led to the development of scales aimed at assessing individual quality of life, such as the Schedule for the Evaluation of Individual Quality of Life (SEIQoL; Hickey et al., 1996). The same methodology was applied by Martin Fegg and coworkers in developing the Schedule for Meaning in Life Evaluation (SMILE; see the article by Fegg et al. (2016) in the present issue).

Both scales start by asking patients about the domains that are most important for their quality/meaning in life, without any restrictions or predefined lists. Respondents are then asked to weight the domains in terms of their relative importance, and to rate their satisfaction with each. This methodology results in strong psychometric robustness while allowing for full display of interindividual variation in life priorities. Not surprisingly, these idiographic assessments are much preferred by patients over nomothetic ones (Neudert et al., 2001), which makes them particularly suitable for clinical use. This approach can also help to overcome the immanent transcultural barriers of nomothetic instruments, such as those described in the article by Maree and van Rensburg (2016) in this issue.

A last important pitfall resides in the tendency of modern medicine to focus on deficits instead of resources. This has resulted in the majority of nomothetic questionnaires focusing on what patients can*not* accomplish any longer, rather than eliciting their available resources. This can actually have direct negative effects on a patient's mood. We have seen several patients with advanced disease burst into tears while completing this type of questionnaire, being reminded time and again of the physical functions they had lost. In our opinion, this strongly calls to task the ethical appropriateness of this kind of assessment in a palliative care setting.

Finally, we should always remind ourselves that assessments of subjective outcomes such as quality of life, meaning life, and spiritual well-being are interventions in and of themselves. With this in mind, it is clearly preferable in clinical practice to address the positive rather than the negative side of issues—for example, to evaluate hope instead of hopelessness, spiritual well-being instead of spiritual distress, meaning in life instead of desire for death. "Negative" scales can be very helpful for specific research purposes, but they should be avoided in patient care. "Positive" scales, on the other hand, can foster communication (we know of several psycho-oncologists who start their consultations with the SEIQoL or the SMILE as "ice-breakers"), elicit important information on patient priorities, and facilitate a resource-oriented outlook on care.

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