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# Importance of Quality-of-Life Measurement Throughout the Disease Course

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In the study by Haslam et al,<sup>1</sup> how often patient's quality of life (QoL) is assessed throughout the patient's disease course is described. The authors included articles from 3 high-impact oncology journals (from July 2015 to July 2018) that assessed QoL as an outcome variable in intervention trials. They included both clinical trials and other (psychological) intervention studies and reported that most studies measured QoL during the intervention period only. Moreover, QoL was rarely measured after progression of the disease and was rarely measured until the end of the patient's life. The findings of the study suggest that QoL should be measured throughout the patient's disease course.

Measuring QoL is a challenge in itself.<sup>2</sup> The underlying reason for including QoL measures in health care was the emerging necessity to consider persons as integrated, feeling, and active beings, not just as biological organisms.<sup>3</sup> From a philosophical perspective, QoL is increasingly considered as well-being, referring to the prudential value of life emphasizing a person's biographical and personal characteristics.<sup>4</sup> The difficult-to-quantify and subjective question, what makes life go well for the individual whose life it is? provides the starting point for discussing QoL. Various studies<sup>5,6</sup> demonstrated that the interpretation of QoL can be difficult partly because a similar score could be interpreted differently throughout the disease course by a single patient. Westerman et al<sup>5</sup> therefore argued that a qualitative approach to evaluate quantitative questions can be worthwhile. Following the perspective that QoL is a difficult outcome measure, herein we focus on QoL throughout the disease course (inside and outside clinical trials) and on measuring QoL with respect to the findings of Haslam et al.<sup>1</sup>

Of interest, Haslam et al<sup>1</sup> did not only include clinical trials in their review. This aspect may evoke bias because most nonclinical trials of cancer are probably more often published in psychological journals. It is therefore not surprising that QoL was rarely the primary outcome measure in the studies. A substantial amount of oncologic clinical trials are performed among patients with some form of cancer in which life prolongation is the primary aim. In approximately half of all patients, positive scores (eg, similar or higher QoL scores compared with baseline) were measured during the intervention period. Thus, in half of all patients, scores were lower during the trial intervention period.

Guaranteeing patient's well-being is essential throughout the clinical trial period and in periods during which patients must wait and see, especially in the context of cancer. Haslam et al,<sup>1</sup> for instance, refer to the long-term effects of anticancer treatment that cannot be assessed during only the trial period, such as with heart failure and cognitive symptoms. Furthermore, a wait-and-see period (eg, periods between first- and second-line treatment) can affect a patients' QoL, for instance, owing to increased insecurity because of doing nothing.

It could be argued whether the current procedure (eg, measuring QoL a few times during the trial period) to evaluate QoL is the right approach. Criteria on toxic effects guide physicians to evaluate whether patients can continue with the trial.<sup>7</sup> A patient's QoL possibly fluctuates daily. Moreover, QoL data probably become available after the patient reported their experiences about the treatment or trial. This delay limits the option for physicians to provide advice to patients with respect to their QoL. Compared with the criteria on toxic effects, QoL is a broader outcome measure that should ideally also be available immediately to provide occasions for treating doctors to evaluate lower QoL scores. Digital measurement of QoL, such as with health applications, will make immediate reporting possibly more feasible in the near future.<sup>8</sup> Such an approach would also facilitate

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measuring QoL during and after specific cancer treatment trials. Moreover, repeated measurements would facilitate the assessment of long-term adverse effects, as suggested by Haslam et al.<sup>1</sup>

In their study, Haslam et al<sup>1</sup> did not focus on a specific QoL outcome measure. It is, however, well-known that, with respect to all QoL outcome measures, response shifts occur; patients automatically shift to other standards and accept their situation.<sup>9</sup> A lower score therefore does not automatically reflect a lower interpretation of QoL. Bloem<sup>10</sup> uses a different concept of QoL, in which only a short questionnaire is used and in which QoL is operationalized in a more holistic way.

Although interpreting QoL remains difficult, a short questionnaire is at least less burdensome and time consuming for patients and therefore is easier to complete frequently to monitor QoL.

In accordance with the suggestions of Haslam et al,<sup>1</sup> we recommend use of different outcome measures to evaluate patients' well-being (eg, criteria on toxic effects, European Organisation for Research and Treatment of Cancer QoL questionnaires, and qualitative evaluations about the patients' QoL). We believe that by doing this, QoL can be measured and monitored broadly to guarantee patients' QoL with awareness of personal and biographical variety.

#### ARTICLE INFORMATION

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