

Rejoinder

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We appreciate very much Dr Kind's insightful comments on our study [1]. Dr Kind points directly to the heart of debate over quality of life (QOL) research: Is there a well-established, standardized instrument that can measure all the relevant facets and dimensions of health-related QOL without bias? If such an instrument exists, can it really quantify, by an interval scale, the quality of life for our patients?

QOL measurement has been increasingly emphasized in evaluating the efficacy of cancer treatment [2]. Most studies compared the impact of different cancer treatments on QOL by reporting the summary scores of QOL questionnaires [3]. The impact on survival is either considered separately from the observed QOL scores or ignored. This may result in a biased estimation of QOL because only living patients provide the follow-up QOL data for comparison [4]. The main feature of our model is to provide a composite measure, allowing for the impact of health service on both the quantity and quality of life, by direct integration of the QOL function and the survival function of a specific cohort [5]. The integration of the QOL and survival functions has a unit of score-time such as score-month or score-year, when QOL questionnaires are used as the instrument for measurement. The results are best interpreted as the cumulative survival-weighted psychometric scores, which is the area under the curve of $Q(t)$ vs. time, for the specific QOL dimension or facet [6]. The best way to test the validity of our statistical model is to put it in the context of controlled clinical trials and correlate the results of the survival-weighted psychometric scores with other objective measurement of the patients' health status.

The questionnaires we used in QOL research indeed reflect the values of the instrument developers. Interpretation and decision on the relative

importance of various dimensions of such profile measures can hardly be truly disinterested [7]. Therefore, the choice of questionnaires depends for a large part on the questions the researchers wish to address. The European Organization for Research and Treatment of Cancer (EORTC)-C30 questionnaire has been shown focusing strongly on the physical functioning and clinical symptoms, which may be especially useful when the aim of the QOL study, such as that of ours, is to compare the effects of different types of treatment [8]. Cancer-specific modules that are developed by several QOL research groups may further facilitate the evaluation of disease- or treatment-related side effects.

We agree with Dr Kind's comment on the scaling issues. Several assumptions are necessary in applying the rating scales [9, 10]. The first is the equal interval of the scale descriptors. The second is the intra-personal comparability, which assumes that an individual subject will perceive in the same way the scale descriptors that define different categories on the rating scale. The third is the inter-personal comparability, which assumes that different subjects will also perceive the scale descriptors on the rating scale in the same way. The fourth is the lack of response bias, which assumes that subjects will provide response without intentional or unintentional distortion. They are quite strong assumptions, and there have been ample arguments questioning their validity [11–17].

There are two approaches trying to untangle the scaling issues. The first approach aims at enhancing the structure of the Likert-type questionnaires. It has been suggested that using Likert's points between 5 and 7 may provide a statistically better approximation to an interval scale and psychometrically distinguishable by human mind [18].

Besides, the same number of Likert points should be used in a measure to reduce the difficulty of obtaining a summation score [19, 20]. The WHO-QOL group recommended a descriptor study, which has been done in the development of the Taiwan version, to select intermediate descriptors that best correspond to the 25, 50, and 75% points between the two 'extreme' anchors for the different types of response scales [21, 22]. This careful choice of descriptors may be the closest approximation of an interval scale for use in the integration with survival on the facet level [23, 24].

The second approach uses mathematical modeling to find out the correlation of the observed item scores with the underlying scale value. Mathematical modeling, such as the Rasch model, the partial credit model, and the rating scale model, can convert ordinal scores to interval scores by nonlinear transformation under several assumptions [25–28]. Alternatively, a ranking procedure has been proposed to substitute for the rating procedure to avoid the strong assumptions of rating scales [29]. However, more studies are needed to test the clinical usefulness of these new methods in quality of life research.

Given the lack of an 'ideal' instrument for QOL research, where can we, as clinicians and researchers who care for the long-term QOL change of cancer patients, go from here? First, we may measure the patients' preference by using utility methods, such as the standard gamble. The QOL function of the study cohort obtained by the utility approach will supplement the QOL data obtained by the profile measure [30]. The utility approach has the features of an interval scale based on several assumptions [31]. Second, we may compare the QOL change between different treatments facet by facet and dimension by dimension, without a judgment of the relative merits, i.e., weighting, of the different dimensions. As we have discussed in our study, different cancer treatments may have differential impact on various QOL dimensions, which can be found more easily by a profile approach. The difference in specific dimensions shown by our approach can help in generating hypothesis rather than making conclusions; the latter can be achieved only by conducting prospective clinical trials. Third, we may conduct several cross-sectional QOL surveys for the same cohort at different time points of follow-up to

improve the accuracy of estimation of the mean QOL function. This longitudinal follow-up will help fine-tune our extrapolation of QOL estimate, too. Fourth, we may correlate the results of the survival-weighted psychometric scores with other objective measurement, such as treatment-related toxicity, in the context of clinical trials. Meanwhile, we are looking eagerly forward to further refinement of the instruments used for QOL research to improve the credibility of health-related QOL measurement.

We all know that the methodology of QOL measurement is far from perfect. The development of our model marks the beginning of our continual efforts in QOL research. We agree wholeheartedly with Dr Kind that we all need to pursue high ideals and standards in our own research. The present study is not the end. It is not even the end of the beginning.

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