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Editorial

Quality of Life and Breast Cancer—the Learning Curve Never Ends

Th. Küchler

Department of General and Thoracic Surgery, Christian-Albrecht Universität, Kiel, Germany

QUALITY OF life and the attempts to measure this construct have been around for about 20 years. The process, that started with early demands by the World Health Organization for instruments to assess quality of life, went through the whole process of discussing the philosophical, psychometric and practical issues related to the term and has now come to a point where reliable and valid instruments to assess quality of life are tested and available. During the same 20 years, the overall treatment of breast cancer changed and improved significantly. It can be argued that the development of breast cancer therapy may serve as a paradigm as to why quality of life research is needed.

The common denominator for both areas was the accompanying controversies, some of which still continue. When primary breast cancer (stage I and II) treatment shifted from radical mastectomy to breast conserving therapy, there was (and on some issues concerning the indication for either treatment still is) a considerable debate about the 'pros and cons'. Fueling this discussion were objective factors such as survival time, as well as more subjective factors, generally related to what today is called 'quality of life'. Now that we know that there are no differences in terms of survival between the two treatment regimens [1], the discussion focuses more on the psychological, social and sexual impact of the given treatment.

When we look at the development of the quality of life area similar debates have been carried out through the years. The first debate was: is it possible to measure quality of life? The answer today is a sound 'Yes and No'. No, we can't measure quality of life, which is a philosophical concept leading to the idea of the best possible way to live your life. Here we meet the philosophical ground with breast cancer therapy. There is no ideal therapy for breast cancer in general, but—theoretically—there is certainly an ideal treatment for each individual patient. For a woman with high level of anxiety, fear of recurrence and a rather poor body image, mastectomy might still be the treatment of choice, even though she is eligible for conservative therapy. This does not change the general perspective that conservative surgery plus adjuvant therapy provide a better outcome for most women whose cancer is detected early compared with 20 years ago.

Back to quality of life. Yes, we can measure limitations in health related quality of life and we can do so in a reliable and valid way. However, if you carefully consider psychometric properties, there are only a few instruments that are reliable, valid and sensitive to changes in patient state. Looking at the short history of quality of life research, there is almost no aspect of quality of life that has not been incorporated into self-tailored instruments. But quality of life is certainly more than a set of symptoms. Review of the literature shows that it focuses on several major areas. Physical, psychological and social functioning, interpersonal relationships and perhaps future prospects seem to be the overall factors that determine quality of life, moderated by spiritual orientation (in a broad sense), family and social belonging and cultural background, as well as by the time factor (Figure 1) [2]. Some believe that it also incorporates the patient's satisfaction with treatment and its outcome.

There are two common errors in using quality of life instruments. Without knowledge about psychometrics, self-tailored instruments may produce sensible as well as erratic results. The literature is full of such reports, where you just do not know what the results mean. The other common error is to define a set of symptoms, usually those which the therapy is targeting, as quality of life. The results of this procedure are commonly known as finding 'self-hidden Easter eggs'. Part of the answer to these problems is quite simple. Use an internationally validated instrument like the EORTC-QLQ-C30, the FACT or the SF 36 and add a diagnosis/treatment specific module. In breast cancer there are such sets of instruments (generic and specific) available [3]. Still there are pitfalls: as breast cancer progresses, the patient's perspective on quality of life changes. These basic principles of human nature have been described by Aristotle and can be summarised as Hofstätter's [4] 'satisfaction formula': evaluation of what you have divided by expectation equals satisfaction. At least two conclusions can be drawn from this formula. First, the doctor's communications skills are moderating the patient's subjective evaluation of quality of life. Second, subjective quality of life changes over time are not necessarily related to objective parameters like disease progress and the treatment provided. For example, a spiritual re-orientation or enhanced personal relationships, once confronted with life threatening illness, have often been described.

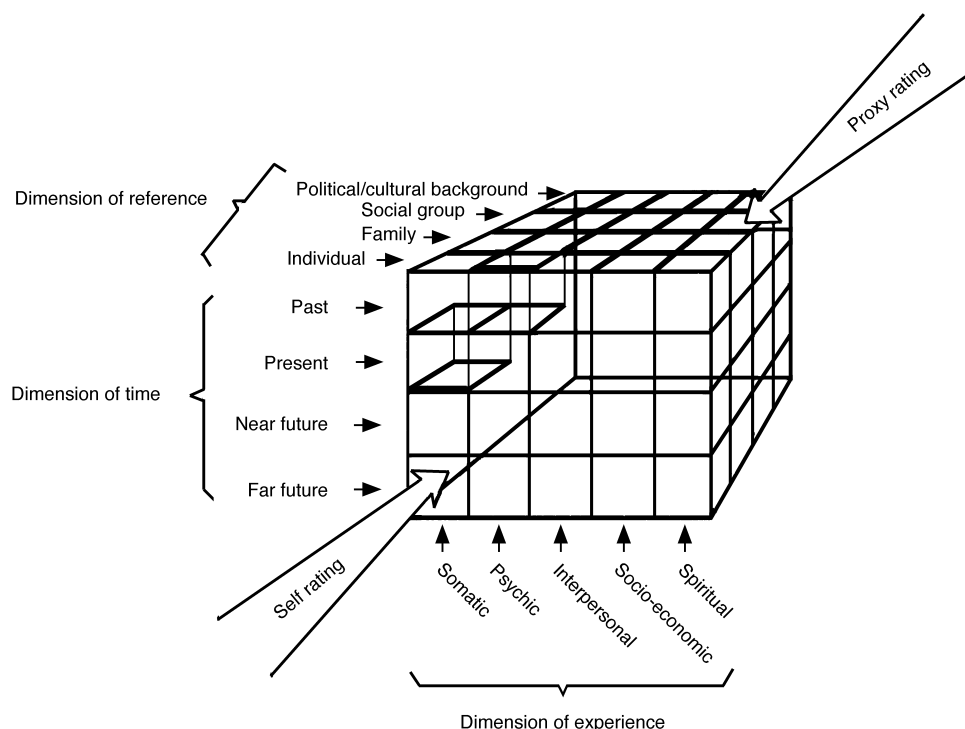


Figure 1. Dimensions of quality of life (conceptual model). Reproduced by permission of Hamburger, Ärzteblatt [2].

The paper by Curran and associates (pp. 307–314) in this issue of the *European Journal of Cancer* marks a milestone for several reasons: first, it covers almost the whole 20 years, during which the previously mentioned changes in breast cancer therapy and quality of life research took place. Within the paper, the comparatively low compliance of both doctors and patients reflects the general attitude in clinical trials toward quality of life at the time of study onset. Today we would expect higher compliance rates, but this paper by itself will foster not only better compliance but genuine interest in those parameters that were called ‘soft’ not so very long ago. The study design might be called visionary since it incorporates patient’s satisfaction (compared with doctor’s rating) and aspects of quality of life (today the study group would probably combine their scales with a standardised instrument), which are today an integral part of quality assurance programmes, not only in breast cancer treatment. Finally it serves as a reminder that quality assurance stands for not just improving overall efficiency, but also making sure that our patients feel as little as possible ‘ashamed, anxious,

embarrassed or concerned’ [5] with the consequences of their treatment. And in this respect, our learning curve should never end.

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