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Placing quality of life assessments on oncologists' agenda

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The last two decades have witnessed a dramatic growth in interest in the assessment of quality of life (QoL) in both oncology research and practice [1–3]. The availability of reliable, cancer-specific instruments for use with cancer patients (e.g., EORTC QLQ-C30, FACT), the changing attitude towards a more biopsychosocial oriented model of clinical practice, as well as the demand by patients themselves and consumer advocacy organizations to address their psychosocial needs as part of quality cancer care have served to bring QoL assessment into the oncologists' agenda. Side effects of treatments have long been a concern for cancer clinicians and were traditionally assessed as a way to understand the impact of therapy and monitor (and when necessary manage) its efficacy. But the QoL concept has evolved from a largely unidimensional biological construct, focused basically on physical symptoms and functional ability, to a multidimensional construct that includes in its definition assessment of other dimensions such as psychological well-being, social functioning, spirituality, etc. [4–6]. Patient's subjective perceptions of their QoL have come to play an important role as medicine has become more patient-centered and patients have become more educated and informed about their illness and treatment options. Increasingly partners in the clinical decision-making process, patients and clinicians strive to balance the various demands of a given therapy with the personal preferences of the patient in

choosing a specific treatment. It is no longer acceptable to pursue "blind survival at all costs" (at the expense of QoL). The European Cancer Patient Coalition (<http://www.ecpc-online.org>) motto of *Nothing About Us Without Us* illustrates how much advocacy organizations emphasize the importance of bringing patients' views into the decision arena, whether it be the singular patient perspective and participating—partnering with clinicians in all decisions affecting their well-being or as Patients' Organizations (Associations or Coalitions) demanding the opportunity to participate in policy-making.

Even if we have come a long way scientifically with respect to the development of reliable instruments to measure patients' QoL, much remains to be done as far as the regular inclusion of these in oncology clinical practice, research, and clinical trials [7]. Regulatory agencies (e.g., FDA, EMEA, etc.), by recognizing QoL as an important endpoint in clinical research, have helped promote the value of QoL assessments, although use of these is not mandatory [8]. Furthermore, the wide range of instruments now available to assess QoL and the lack of guidelines for which to choose in a given clinical or research scenario or how to interpret the resulting data have been a deterrent in this process.

The paper featured in this issue of *Supportive Care in Cancer*, "The clinical significance of quality of life assessments in oncology: a summary for clinicians," is an important con-

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tribution to reduce this gap. The authors, Jeff Sloane et al., are part of the Clinical Significance Consensus Meeting Group. The group comprised of 30 QoL research experts, who first met in 1999 and then again in 2000 at the Mayo Clinic in Rochester, Minnesota, with the express purpose of discussing these issues and reaching some consensus guidelines about QoL assessments and interpretation that would facilitate their use for clinicians, researchers, and regulators [9]. As a result, six articles were published concerning the *state of the science* of QoL assessments in oncology in 2002 at the Mayo Clinic Proceedings [10–15] in a special section dedicated to the Symposium on Quality of Life in Cancer Patients.

In the present paper, a more readily digestible, updated and summarized version of the more extensive set of articles, the authors intend to provide clinicians with simplified information that would help them better understand QoL assessments and influence their decision to include these routinely in their clinical practice and research. Core issues for QoL assessment and interpretation are addressed and recommendations are illustrated with a practical application of a lung cancer clinical trial example, which promotes a better understanding for the clinician of the more theoretical content explained and its applicability. The 63 references provided are also rich resources for those who want to further delve into certain topics, and the tables and figures are provided to clarify some of the concepts.

The paper highlights six key challenges to QoL assessment as delineated by the Consensus Meeting Group in each of the articles:

(1) *Methods to explain the clinical significance of QoL measures* in which the difference between statistical significance and clinical significance is clarified, and useful strategies used to date are presented to facilitate the interpretation of QoL results.

(2) *Group vs individual approaches to understanding the clinical significance of differences or changes in QoL* clarifies the methods that can be used, inductive or deductive, in interpreting individual data.

(3) *Assessing the clinical significance of single items relative to summated scores* presents the pros, cons and specific indications of choosing a single item questionnaire (like VAS) or a multi-item questionnaire.

(4) *Patient, clinician, and population perspectives on determining the clinical significance of QoL scores* pertains to how these different perspectives, each one having their own standards and values, perceive change in QoL.

(5) *Assessing meaningful change in QoL over time: a user's guide for Clinicians* addresses relevant issues to help clinicians in the decision-making process regarding the selection of the optimal treatment for each patient and how to do so from understanding and interpreting longitudinal QoL data presented in the literature.

(6) *The clinical significance of QoL results: practical considerations for specific audiences* introduces the meaning or interpretation of different QoL outcomes from the patients', clinicians', and policy-makers' perspective, and how this clinical significance can best be communicated to patients as health-relevant information that could assist the treatment decision-making process, in a successful way for both patient and clinician and their relationship.

Hopefully, after reading this paper clinicians will have greater confidence in their ability to use QoL assessments and appreciation of the utility of the data they provide in helping them facilitate shared decision-making with patients and improve treatment compliance. It is also hoped that the information provided will

encourage readers to recognize that the current QoL measures are scientifically reliable tools with the potential, when incorporated into research and clinical trials protocols, to yield added benefits for patients and oncologic science alike.

In conclusion, the incorporation of QoL assessments and endpoints into clinical research and practice is a winning situation for all the partners involved. For the patients, it addresses their perceptions of well-being and brings their perspective into play, conveying the message that they are at the center of care, their opinion matters, and that the focus of treatment and health care is appropriately on their personal sense of well-being. Use of these evaluations also serves to foster patients' awareness and responsiveness to their QoL aspects and promotes an informed participative and partnership attitude. For professionals, use of QoL assessments gives them outcome data that can be meaningful for them and the patients they treat to apply in treatment decisions. It also heightens their awareness of patients' well-being and facilitates discussion of QoL issues [16]. Because emotional and social dimensions are a standard part of QoL assessment, use of these tools can also provide a way to screen for distress, affording clinicians a means to systematically recognize psychosocial problems or morbidity associated with illness and treatment (a problem addressed elsewhere [17]), and make the proper referrals for evaluation or support, thereby contributing to a better quality of life for their patients. Addressing these often neglected aspects of patients' functioning can in turn have positive implications for patients' overall well-being, their satisfaction with care, and given that mental health interventions have been shown to reduce health care utilization, potentially, health care costs.

Placing QoL assessments on oncologists' agenda is thus a step forward in reaching better quality, patient-centered care.

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