

Patient-Reported Outcomes and Managed Care Decisions: Quality of Life and Related Components

Georgia Vogelsang, MD; and Julie R. Brahmer, MD

This supplement to the *American Journal of Managed Care* discusses some of the achievements and challenges of quality of life (QOL) research and assessment, including methodology and use of measurement tools, in patients with cancer. Health-related QOL research has helped define and draw attention to the human side of cancer treatment and has influenced the treatment itself. Although measuring QOL is a difficult task, QOL is an integral part of cancer patient management. The improvements in health-related QOL research that have taken place over the past 3 decades have helped this field of research become increasingly accepted by the medical community and society at large. Clinical trial-based health-related QOL data are now being used with greater frequency in Food and Drug Administration–approved marketing. QOL assessments have not only been useful in clinical trials and cost-effectiveness studies, but have also pointed to physical, cognitive, and psychosocial areas. Health-related QOL data have been found to be strong predictors of survival and have proven to be useful in clinical care studies, particularly in stimulating physician–patient communication of psychosocial issues. The material presented here should be helpful in providing clinicians and administrators with information to help in treatment decision-making and cancer care.

The first article in this supplement, by Carolyn E. Schwartz, ScD, and Mirjam A.G. Sprangers, PhD, provides an intro-

duction to the concepts encompassed by QOL research, describes the documented uses of such outcomes, and highlights the challenges that need to be addressed as patient-reported outcomes (PROs) are increasingly considered. The authors discuss the emphasis on accountability in healthcare and how this discipline seeks objective and subjective assessments of the effectiveness of medical intervention on patient outcomes. As a result of this activity, methods that integrate PROs into treatment assessments are becoming increasingly utilized, and the prevalence of peer-reviewed journal articles reporting PRO research has expanded significantly. The authors note that patients usually have the best perspective on the impact of a treatment because they experience first-hand the obvious benefits and burdens of treatments as well as being aware of the hidden benefits and costs of a treatment that may solidify or threaten stringent adherence to provider recommendations. Asking patients about their perspectives has the potential to yield clinically meaningful end points that are an integral part of clinical decision-making. Thus, PROs address the fundamental value of a treatment, over and above the treatment's effect on measurable objective parameters of health.

The next article, by Mehul K. Soni, PharmD, and David Cella, PhD, provides an overview of QOL and symptom measures used in oncology. This paper clarifies the definition of QOL, provides a brief overview of several useful measurement instruments, and addresses some com-

mon concerns encountered in measuring QOL in cancer patients. In addition, potential uses of such measures are explored, and their value in various settings, including managed care, are highlighted. Because improving QOL in oncology patients is an important therapeutic goal, most treatment decisions are heavily influenced by their effect on QOL. Instruments used for measuring QOL and symptom burden range from general health status measures to considerably more focused symptom measures. These measures have a potential impact in the managed care environment because they provide information on patient satisfaction and quality of care provided.

The third article, by Marlene H. Frost, RN, PhD, and Jeff A. Sloan, PhD, challenges the view of QOL measurements having a soft outcome, as opposed to the type of outcomes that provide hard end points or factual data and can be easily defined quantitatively. The authors discuss how the softness of QOL outcomes relative to such hard outcomes as survival and tumor response is cited as a particular barrier to implementation and interpretation of results. This paper reviews the importance of QOL to clinical practice, discusses the perceived softness of QOL, and compares the roles of symptoms and QOL scores as they relate to disease progression and tumor response. The authors believe that providing sound QOL data to

healthcare professionals and patients is essential to enable truly informed decision-making.

The final article in this supplement, by Cheryl R. Dennison, PhD, CRNP, discusses how PROs are used in evaluating the quality of oncology care. Because the science of oncology care is rapidly developing, a considerable variation in treatment patterns and disparity in the quality of care is seen. Dr. Dennison discusses how efforts to evaluate and improve the quality of oncology care are under way, as the goals of care have progressed beyond reducing morbidity and mortality to include maximizing functional and cognitive status, improving health-related QOL, and preserving productivity. Although traditional indicators of quality of care were based on survival outcomes or the processes of care, they are currently inadequate for evaluating the multidimensional goals of care. PROs would enhance the evaluation of the quality of care by including a patient perspective. A model for measuring quality characteristics is proposed. The inclusion of PROs in the model is essential to ensure that it evaluates the quality of care from a multidimensional view with value placed on the patient perspective. To appropriately inform decision makers, methodology must include rigorous risk adjustment methods, as well as PROs that are valid, reliable, sensitive, and feasible.