

# Considering the Value of Quality of Life Research in Managed Care Medicine

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TODAY'S MANAGED CARE industry has played a major role in shaping the delivery of medical care in the U.S. As the landscape of healthcare has evolved, managed care has changed in tandem to address the needs of the multiple stakeholders it serves. One important development in the delivery of medical care is the increased attention to patient *quality of life* (QoL) research and related health outcomes.

Increasingly, patients and their families insist that QoL be considered as an outcome of their care during and after medical interventions, as treatment options are discussed. These requests are supported by data demonstrating QoL to be a predictor of survival, a useful tool in stimulating physician-patient communication, and a valuable input to clinical care and informed health decision making (Vogelsang, 2002). As such, one can see the potential advantages of including QoL in decision-making for the patient, for family members, and for the clinical team.

However, a key question remains: how can the inclusion of QoL benefit managed care organizations (MCOs)? If the mortality or morbidity benefits of treatment appear to be marginal, as may be the case in certain late-stage or chronic ill-

nesses (e.g., cancer, congestive heart failure), how can QoL data add value in assessing coverage or formulary placement, and in delivering medicine's promise of high-quality, patient-centered care? This question is poignant in an era where healthcare stakeholders are increasingly faced with the challenge of balancing the quality and cost of care, including costs associated with some emerging treatments that might predominately yield QoL benefits.

## What is Quality of Life?

Before discussing the value of QoL research, one must establish a basic understanding of QoL. In general, the concept of QoL has developed during the past 20 years, and reflects the "whole-person care" model utilized in palliative medicine. QoL is best described as subjective and multidimensional: subjective in that each patient's perspective will be different, and multidimensional because it focuses on a wide range of areas including functional ability and physical, emotional, social, and spiritual well-being (Cella, 1994). An expanded concept of QoL may also include the benefits and individual preferences of patients relative to their personal function and overall "whole-person" well-being (Exhibit 1). Using this framework, how do MCOs practically consider the costs and benefits of various treatment options relative to the subjective perception of the overall patient's well-being and at the same time offer cost-effective health plans?

If managed care is thought of as a system of healthcare delivery with the goal of controlling costs while providing quality care, an approach that incorporates QoL needs to be evidence-based and benefit the key stakeholders involved. As such, valid and reliable QoL data must be gathered and

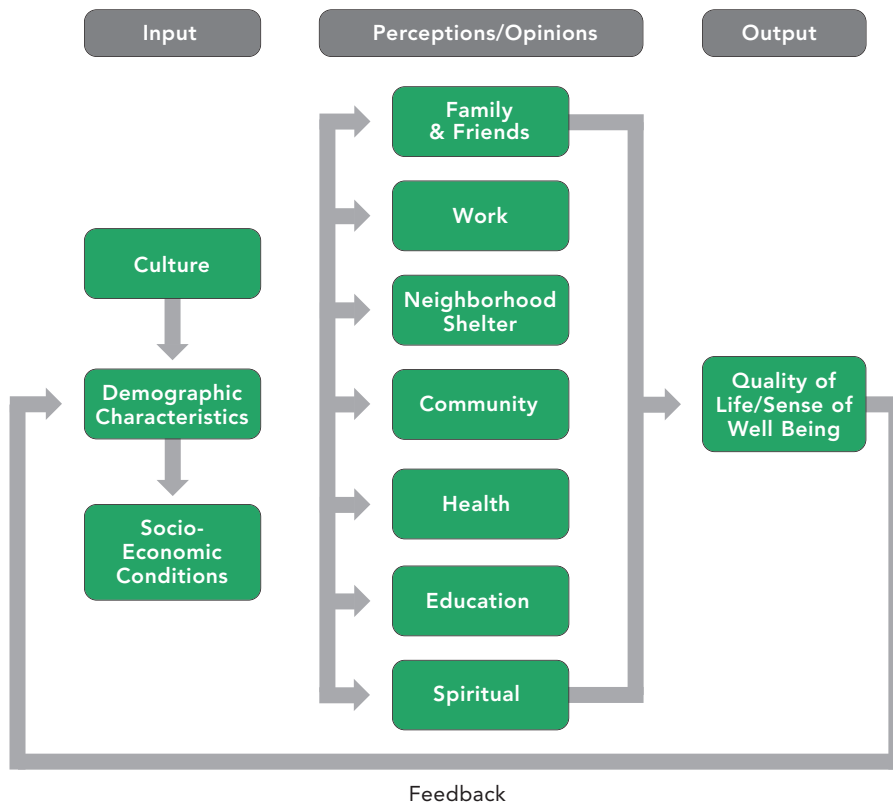
appropriate systems must be in place to collect and disseminate this data to decision-makers. Such information could potentially be integrated into clinical practice guidelines. QoL data is also relevant to broader healthcare transparency initiatives, such as those currently being developed by the Centers for Medicare and Medicaid Services (CMS), that seek to broadly communicate information on the value, quality and affordability of health services.

On the other hand, health interventions based on QoL data must also be demonstrated as cost-effective for the patients, physicians, employers, and health plans involved in receipt and administration of these services. Some health decision-makers may perceive QoL to be a lower priority or less-actionable option in the continuum of pressures that confront modern medicine. Without actionable evidence or proof of the value of QoL in improving patient outcomes, payers, employers and others may be reluctant to invest in patient QoL. This article will discuss the potential value of integrating scientifically sound QoL research into the decision-making process of managed care, its potential cost-effectiveness, and health outcomes and patient satisfaction.

## Valid and Reliable QoL Research Measures

The utility of QoL measures has been widely debated in medical literature. Often, QoL research and measures are regarded as being a "softer" science, because physiological end points to alleviate or stabilize disease have long been considered the gold standard in medical research (Frost & Sloan, 2002). One of the reasons why treatment response has been preferred over QoL is the idea that a cure or means to stabilize a disease can and will be found. While this

Exhibit 1: Quality of Life: A Systems Model



The University of Oklahoma School of Social Work ([www.gdrc.org/uem/qol](http://www.gdrc.org/uem/qol))

is indeed the desired outcome, it is simply unrealistic for many conditions and does little to address the needs of patients living with illness today. Another misconception is that treating illness may be done in isolation, as if treatment, whether aggressive such as surgery or chemotherapy or noninvasive such as exercise or nutritional advice, will not impact the patient in some other way. In this respect, integrating a system that collects QoL data along with other inputs helps the medical community adhere to its oath, “to do no harm.”

In the past, the perception that QoL research produced little meaningful data had some validity because qualitative tools to address the subjective and multidimensional aspects of QoL did not exist.

This is no longer true of today’s QoL measures and research. QoL measures have come a long way. There are now sophisticated methods and instruments for collecting QoL data. In general there are two types of QoL instruments: generic and disease-specific. A generic tool, like the SF-36, is a broad instrument that allows researchers to focus on differences between illnesses or treatment regimens. Disease-specific instruments focus on the effects of illness and treatment within a certain disease population. An example of this would be the Functional Assessment of Cancer Therapy-Brain (FACT-BR). For an overview of commonly used QoL instruments used in by MCOs, go to [www.medscape.com/article/41002](http://www.medscape.com/article/41002).

However the simplest explanation of why QoL research appears to have lagged behind, and is slowly being integrated into managed care formularies, has to do with the fact the QoL has just hit its stride in comparison to medical and quantitative research.

A major barrier to incorporating QoL assessment with functional data is the lack of information systems to collect such data. Clinicians and MCOs routinely collect functional information like diagnoses and treatment patterns; however, they are still some way from achieving an integrated approach. Collecting QoL information systematically is much more difficult due to a lack of technology to capture this data. However, new systems, such as e-pads that mea-

sure QoL along with functional status, are being evaluated at multiple medical centers in the U.S. Such approaches, in tandem with the rapid evolution of electronic health records, may in the near future enable QoL data to be collected and assessed with greater ease and efficiency.

### **How Can QoL Help with Cost Effectiveness?**

Traditionally, medical outcomes have been measured in enhanced survival or lower complication rates. However, in today's managed care market, cost and factors such as a patient's ability to return to work or pursue desired activities, are becoming important factors for all involved. Patients want to feel better and return to activities of daily living, employers want their employees to return to work, and MCOs want to provide cost-effective, quality care. Each of these scenarios is linked financially/economically to other stakeholders in the managed care healthcare delivery equation. So how might QoL research help patients, employers, clinicians, and managed care organizations with costs?

The inclusion of QoL data in the decision-making process can help to initiate a physician-patient dialogue about both the costs and benefits of available procedures and treatments. For example, QoL research has been shown to be a critical factor in better understanding new therapies, not simply in terms of survival, but in terms of what that additional survival means to the individual patient (Bottomley et al., 2005; Osoba, 2002). As emerging health technologies produce longer survival rates and other benefits, patients logically want to know what the quality of those

extended years will be like (Pinson et al., 2000). As the cost burden continues to shift towards the employer and individual patient, many are demanding information on the value obtained for their healthcare expenditures. Each healthcare decision is not without specific monetary cost to the patient, clinician, and MCO.

As previously mentioned, the inclusion of QoL data may also prove to be especially important when there is no clear survival advantage among treatment options, but potential QoL outcomes are quite different (Peterson

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& Sonis, 2001). Robust QoL data regarding available care options can increase patient understanding of decision tradeoffs and anticipated short- and long-term impacts on health outcomes. Using this same information, clinicians and MCOs also can make better informed decisions concerning the cost versus benefit of treatment modalities that may appear to be equivalent using conventional metrics.

### **How Does QoL Relate to Health Outcomes and Patient Satisfaction?**

If MCOs are to truly under-

stand health outcomes, there must be a critical evaluation of the complex relationships among intensity of illness, duration of illness, and overall QoL. Currently, the units used to measure the utility of healthcare interventions are quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs). These measures allow medical interventions to be compared in terms of cost-effectiveness, without implication as to the monetary worth of an individual's life. However, QALYs or DALYs do little to assess the subjective or multidimensional components that

might be important to an individual's overall well-being. Further, many U.S. MCOs have been reluctant to fully embrace such economic measures in reimbursement decision making versus their international counterparts in Canada, Europe and Australia.

To address some of these shortcomings, a growing field of research exists that applies methods of QoL research within health-related research such as clinical trials. This departure from global QoL has been named health related quality of life (HRQoL). The addition of HRQoL research to

traditional outcomes research allows for a much broader understanding of health outcomes associated with medical interventions. Whereas, current methods look solely at the objective cost-effectiveness of an intervention, HRQoL accounts for the patient's subjective perception of post-medical health status. Incorporating such measures provides clinicians and MCOs not only with the quality and cost information needed for informed decisions, but also the broader patient perceived health benefits of the intervention.

Simply assessing patient QoL in

a clinical setting may go a long way towards increasing patient satisfaction. First, it sends a clear statement to the patient that the clinician, center of care, and managed care plan are interested in more than just treating an illness or conserving resources. QoL has an additional scientific advantage that other end points lack: it allows for a difference in opinion between the clinician and patient, creating an opportunity for open dialogue. Improving such dialogue has been cited by many as a national priority, particularly as pressures of the modern health-care environment widen the gap between physicians and patients.

Furthermore, today's healthcare marketplace offers patients many competing therapeutic options. Explanation of QoL implications of different therapeutic regimens may enhance treatment decision making by patient, family, and health providers. Indeed, when patients gain a realistic understanding of post-treatment outcomes in terms other than disease-free survival (Peterson & Sonis, 2001) and the factors influencing good or poor recovery, the value of QoL to patient awareness and quality of care becomes more transparent (Andrykowski, 1994).

### Can MCOs Use QoL Data in Health Decision Making?

Incorporation of QoL data into the decision systems of MCOs may be particularly timely in an era where the overall health dynamic of the U.S. continues to shift. Factors such as the aging U.S. population, expanding definition of treatable disease, and desire for ever more promising medical solutions have driven development of technological advancements in genomic and stem cell research, biopharmaceuticals, and other areas. How we assign value to such advancements and their attendant health out-

comes remains a significant challenge for many health stakeholders. Considering patient QoL is one increasingly important part of this value assessment process.

For example, the treatment of cancer is constantly improving. With a large population of patients living longer than five years, survival is no longer the only outcome of importance. QoL, then, begins to play a greater role in the context of patient care for many diseases.

As clinicians, patients and employers become increasingly concerned with QoL both during and after treatment, how can MCOs practically identify those circumstances where QoL information is beneficial to the delivery of high quality and fiscally responsible care? What criteria, including QoL measures, are most relevant to comparative selection of treatment alternatives by the patient, physician or MCO? Under what scenarios or for what diseases is QoL data most feasible and relevant to informed health decision making? What specific evidence collection and dissemination systems must be in place for better integration of QoL and at what cost? Are the benefits of obtaining and using QoL data in addition to other clinical/outcomes data proven or perceived by health decision makers to outweigh these costs?

While the utility of QoL research and data is better understood today, many questions remain regarding integration of this information into managed care systems facing significant quality and cost pressures. Some of the potential benefits for MCOs include the ability to initiate dialogues concerning cost vs. benefit, a better understanding of the value of medical interventions and overall health status, strengthening of physician/patient relationships, and increased patient satisfaction and medication compliance.

Nevertheless, MCOs are still just in the early stages of collecting and integrating QoL research. Because of the practical challenges cited above, it may be some time before QoL research and data is fully integrated into the decision-making process of MCOs and its true benefits are known. Only time will tell if MCOs will continue to invest their time and money into the QoL process. Despite its potential benefits, the financial investment vs. the value added by QoL research and outcomes can only be determined within the financial balance sheets of MCOs. **JMCM**

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