

Measuring and Monitoring Health-related Quality of Life Among Patients with Chronic Kidney Disease

a report by

Mark L Unruh, MD, MSc

Assistant Professor of Medicine, University of Pittsburgh

Mark L Unruh, MD, MSc, is an Assistant Professor of Medicine at the University of Pittsburgh and also serves as the Sub-Specialty Education Coordinator for the Renal-Electrolyte Division of the University's Department of Medicine. Dr Unruh has participated in the CHOICE (Choices for Healthy Outcomes in Caring for ESRD) Study and the Hemodialysis (HEMO) Study as a co-investigator and serves as the principal investigator of the Quality of Life Care for the Frequent Hemodialysis Network (FHN) Study. He has written over 30 articles and book chapters and received grant support from the National Institutes of Health (NIH), National Kidney Foundation (NKF), American Society of Nephrology (ASN), and the Paul Teschan Research Fund. Dr Unruh is an active member of the NKF and the ASN. He received his MD from the University of Chicago and served his residencies at the University of Pennsylvania in Philadelphia and at Tufts-New England Medical Center in Boston, Massachusetts.

The health-related quality of life (HRQOL) of patients with chronic kidney disease (CKD) is a critical and yet overlooked aspect of the disease experience. This is particularly true for dialysis patients who choose not to receive a kidney transplant and those with substantial comorbidities who are not candidates for renal transplantation—that is, patients who are effectively confined to the chronic rigors of maintenance dialysis therapy on an indefinite basis. In addition, the aspects of HRQOL that change following the initiation of renal replacement therapy tend to be highly individual and may include change in the level of physical activity, loss of employment, and change in the person's social role. This health transition needs further study. This report will examine the conceptual model and definition of HRQOL, and measurement of HRQOL, and review the importance of assessing physical functioning, symptoms, pain, mood, and sleep quality. Measuring and monitoring this in CKD patients can be accomplished with the widespread implementation of HRQOL assessment.

HRQOL pertains to health demands that are intimately related to health or disease. These health states are based on the World Health Organization (WHO) definition of quality of life as a complete state of physical, mental, and social well-being and not merely an absence of disease and/or infirmity. This model of HRQOL is shown in *Figure 1*, which adopts the WHO definition of quality life to the treatment of CKD. This model recognizes an overall HRQOL that includes perceived health, happiness, satisfaction, and spirituality. The model acknowledges the importance of psychological, social, and physical functioning to perceived HRQOL. The definition of overall quality of life is broader and may include domains not as influenced by healthcare or disease, such as leisure activities, religiosity, or certain aspects of family relationships.

The Measurement of HRQOL in CKD

It has been shown that humans are capable of numerical assessment of qualities for which there may be no physical signs, such as pain, severity of depression, physical health, and overall HRQOL. The assessment of physical functioning was an early outcome among

clinical investigators. Next, investigators explored patient self-report of symptoms, comorbidity checklists, and one-dimensional (1-D) HRQOL scales, such as instruments measuring only bodily pain or social function. More recently, patients have been assessed with multidimensional HRQOL assessments. 'Generic' multidimensional HRQOL measures are designed to provide information about function and well-being that allows for comparison of individuals regardless of their specific condition. In contrast, 'disease-targeted' multidimensional HRQOL questionnaires collect information that is targeted towards the characteristics common to a subgroup of a population. The most comprehensive assessment of HRQOL includes an assessment of both generic and disease-targeted content. The treatment goals of CKD have evolved over time—as shown in *Figure 1*—so that patients have not only an expectation of survival, but they also expect to achieve a certain level of well-being. In the future, it may be that patients demonstrate their own preferences for the domains of HRQOL that are important to them and weigh the relative importance of these domains to their sense of well-being.

For HRQOL assessment, data may be gathered by self-report, observer ratings, informant—also known as a proxy or surrogate—ratings and archival data. There are disparities between informant ratings and the patient ratings of HRQOL, although informant may still provide useful data. Self-reported HRQOL information may be gathered by pencil and paper surveys, face-to-face interviews, telephone interviews, or interfacing with a survey using computer software on the Internet. The Hemodialysis (HEMO) Study investigators found that many patients could not complete the surveys on their own because of physical limitations related to impaired dexterity or visual disturbances, as well as strong patient preference, which may have included those with limited reading skills. Those patients that required the help of an interviewer were more likely to be older and sicker than those who completed the survey using pencil. In general, HRQOL scores of those that were face-to-face interviewed were higher than would be otherwise expected. It may be that the lack of privacy and/or potential role of the interviewer in the care of the patient

may influence such patients' scores. Nonetheless, both the patient population and burden to staff should be considered when using selecting the mode of administration of HRQOL instruments for research or patient care. Further work characterizing the use of telephone and Internet administration of HRQOL survey in patients with CKD would help to expand the potential number of patients using HRQOL assessments.

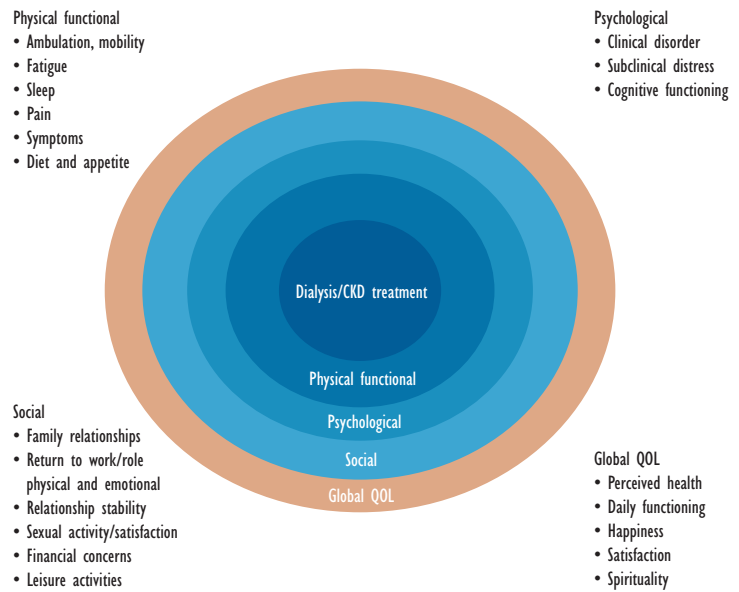
An ideal HRQOL instrument is multidimensional and incorporates generic and disease-specific measures. An ideal measure would be sensitive to clinical change in patients, easily compared with normative data, able to be administered and scored by lay personnel, and have a limited patient and administrative time burden. Overall, the reliability of widely used HRQOL surveys in patients with CKD compares favorably with widely used clinical measures such as blood pressure and submaximal exercise tests in patients with chronic obstructive pulmonary disease (COPD).

The importance of HRQOL has been increasingly recognized by those who pay for healthcare, as well as by healthcare providers, regulatory agencies and by researchers, both within and outside the renal community. To date, the assessment of HRQOL in the CKD population has been largely confined to the research setting and to patients undergoing hemodialysis. Multiple studies have shown that the HRQOL of patients receiving maintenance dialysis is markedly impaired compared to the general population and to patients with ESRD who receive kidney transplants. Such observations underlie the importance of translating HRQOL assessment from the research domain to the clinical arena. Although there are facets of HRQOL that may not be amenable to provider intervention, there are domains such as symptoms, pain, mood, sleep quality, and physical functioning that targeted interventions may be able to address and, in turn, improve overall HRQOL.

Symptom and Pain Management

A series of studies have demonstrated that physical and emotional symptoms are both highly prevalent and frequently severe in patients dependent on maintenance hemodialysis. Weisbord et al. examined symptom burden and severity in a cohort of 162 maintenance hemodialysis patients. Patients reported an average of greater than nine symptoms. This is comparable to the number of symptoms seen in AIDS and cancer populations. Pain, fatigue, and itching were among the most commonly endorsed symptoms in our study, reported by more than half of study subjects. As part of a study investigating the utility and acceptability of a palliative care intervention in highly comorbid hemodialysis patients, Weisbord et al. assessed the correlation between patient-reported

Figure 1: HRQOL Outcomes of CKD Support



symptoms on a symptom assessment questionnaire and symptoms that renal providers document as being present in patients' dialysis charts. Only 40% of symptoms endorsed by patients on the questionnaire appeared in the progress notes of patients' charts, suggesting that renal providers may not be adequately evaluating their patients for troubling symptoms. More recently, Davison studied pain and its treatment in a cohort of 205 hemodialysis patients. Pain was present in 50% of patients, yet more than one-third of those with pain were receiving no analgesic therapy for this complaint.

At our own institution, we use a symptom index to follow patients who have advanced CKD, including those who initiate home dialysis therapies. We have found several instances in which these 'standardized' assessments validate clinical impressions and support the importance of clinical interventions. There are situations in which patients do not respond to provider-initiated questions about symptoms, yet endorse the presence of multiple symptoms when asked to complete a symptom survey. Strong patient-provider relationships and open communication are essential to interpreting the clinical significance of such discrepancies.

Depression has been found to be the most common psychiatric disturbance in patients on dialysis, with as many as 20% of patients on renal replacement therapy suffering from it. Kimmel and colleagues conducted a longitudinal cohort study of 295 hemodialysis patients using the Beck Depression Inventory to assess depression over a two-year period. Their work demonstrated that the level of depressive affect was associated with an increased risk for mortality. Most HRQOL assessment tools used in patients with ESRD have components that measure

mental/psychological well-being, suggesting that such instruments could be used to help identify depressive affect. The use of a subjective assessment of depression among dialysis patients could provide an opportunity to address an important and potentially treatable component of the disease experience of those on dialysis.

Sleep disturbances may lead to daytime sleepiness, decreased mental acuity, and, subsequently, poor daytime functioning of those on dialysis. In the general population, the treatment of sleep apnea with continuous positive airway pressure (CPAP) improves quality of life, vigilance, cognition, and sexual performance. In those with congestive heart failure, the treatment of sleep apnea was shown to improve HRQOL measures, but not survival. In a very small study of patients with ESRD, CPAP was associated with small improvements in nocturnal oxygenation and daytime alertness. HRQOL assessment tools contain a variable number of items pertaining to sleep. The assessment of self-reported sleep quality by clinicians to identify the presence of sleep disturbance could greatly facilitate the diagnosis and treatment of sleep disorders in patients, with resulting improvements in overall HRQOL.

Many physicians evaluate their hemodialysis patients while the patient is seated in a dialysis chair. Formal assessments of physical functional and capacity may be quite limited in practice and in scope. The assessment of patients' physical functioning using a HRQOL survey could help providers diagnose physical impairments and propensity for falls. Moreover, formal assessments of functional capacity could facilitate the referral of select patients for physical or exercise therapy, which has been shown in some studies to be an effective intervention for functional impairments.

Several studies have revealed an underutilization of advanced directives in patients with ESRD. Palliative care consultative services have been established in many medical centers to help address the needs of patients with advanced illness. Preliminary data demonstrate that such services can reduce symptom burden, favorably impact specific domains of HRQOL, and help patients complete advance directives. Among dialysis patients with substantial comorbidity, the input of a palliative care service was highly acceptable to both patients and renal providers. There also was little correlation between the physicians' perception of symptoms and the reports of patients with kidney failure. Formal HRQOL assessments among dialysis patients could help identify patients with very poor HRQOL, significantly impaired functional status, and limited social support—patients who might benefit from a palliative care intervention.

Barriers to the Application of HRQOL Assessment

Despite the apparent need and potential benefits of HRQOL assessments in dialysis patients, there are limitations to the use of such assessments in clinical practice. The adaptation of HRQOL assessment by clinicians could be likened to the diffusion of any novel laboratory test in clinical practice. Similarly, it may be difficult for providers to understand the meaning of an individual's score on a HRQOL assessment measure and/or how to interpret a change in the score. Efforts to address this problem hinge on familiarizing providers with the instruments that are available for HRQOL assessment in the dialysis population and their scoring. A second limitation to the implementation of HRQOL assessment in clinical practice relates to the inherent limitations of the individual questionnaires. One alternative to using HRQOL surveys with a large number of questions would be to employ assessments of specific facets of HRQOL, such as symptom burden, depression, or physical functioning. Another exciting approach to HRQOL assessment has been the development of computer adaptive testing (CAT), which permits the response of the patient to inform the selection of the next question. In this way, the length of HRQOL questionnaires may be dramatically shortened, since the person who can walk a mile does not need to be asked if he/she can walk a block. The use of CAT with HRQOL surveys would allow physicians to gather a great deal of reliable data, while limiting the burden of survey administration on the patient and the staff.

HRQOL Assessment—Opportunity to Improve Care

The routine use of HRQOL assessments in the care of patients with CKD represents an important opportunity for healthcare providers. The barriers to HRQOL assessment have been addressed by the proliferation of HRQOL reports in studies of patients with CKD and by leaps in HRQOL assessment technology. Facets of patients' lives that could be favorably influenced by standardized assessments of HRQOL include—but are not limited to—the recognition of symptoms and psychological illness such as depression, diagnosis of sleep disorders and impairments of physical functioning, and identification of patients who might benefit from the input of specialists in palliative care. Measuring and monitoring these aspects of quality of life will lead to a more patient-centered care and improve the health and well-being among patients with CKD. ■

An version of this article containing references and additional figures can be found in the Reference Section on the website supporting this briefing (www.touchgenitourinarydisease.com).