

Chapter 35: Methods to Assess Quality of Life and Functional Status and Their Applications in Clinical Care in Elderly Patients with CKD

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Elderly patients and their caregivers are faced with a wide variety of complex treatment decisions ranging from the risks and benefits of antihypertensive therapy to the decision to pursue renal replacement therapy *versus* palliative care. There is a great deal of heterogeneity in health status among elderly patients with chronic kidney disease (CKD) and end-stage kidney disease (ESKD), and age alone cannot reliably predict outcomes. In addition to measures of disease severity and psychosocial function (discussed elsewhere), measures of quality of life (QOL) and functional status may provide useful information to aid in prognostic stratification and help guide treatment decisions. QOL and functional status themselves are important outcomes that need to be carefully considered along with survival when evaluating treatment options. In this context, we review the methods to assess QOL and functional status, and their applications in clinical care, focusing on ESKD-related interventions and outcomes.

HEALTH-RELATED QUALITY OF LIFE

Quality of life (QOL) is a concept that most people intuitively understand, yet is difficult to define precisely. Most definitions of QOL are centered on the notion of health put forth by the World Health Organization as “a state of complete, physical, mental and social well-being, and not merely the absence of disease or infirmity.”¹ Health-related QOL (HRQOL) focuses specifically on the influence of health, illness, and medical treatment on QOL.

GENERIC VERSUS DISEASE-SPECIFIC ASSESSMENTS

HRQOL assessments are divided into two general types: generic and disease specific. Generic assess-

ments allow for broad evaluation of overall health across many different domains. In addition, because generic assessments are geared toward the general population, they allow for comparisons with different groups of patients and interventions. However, generic assessments may inadvertently bias results toward or against subsets of the general population. For example, a generic assessment with an emphasis on physical functioning may suggest poorer results for elderly persons or patients with mobility-limiting conditions such as rheumatoid arthritis.

In contrast to generic assessments, disease-specific assessments are designed for patients with a specific disease or undergoing a particular intervention. However, disease-specific assessments may not accurately reflect QOL if they lack items pertaining to dimensions of the disease that affects QOL (e.g., an ESKD scale that does not assess pruritus). Another limitation of disease-specific assessments is that because they are developed specifically for use in a particular disease state or for assessment of a particular intervention, it is difficult to compare the results to a different population.

METHODS TO ASSESS HRQOL

There are many different types of QOL assessments available. It is important when choosing a HRQOL assessment tool to understand the context and patient population in which the tool was developed, because this affects the reliability and validity of the

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Table 1. Common HRQOL instruments

Test	Domains Tested	Time to Complete (min)	Validated in ESRD	Validated in Elderly	Resources
SF-36	Physical functioning Limitations in usual role activities due to physical health problems Bodily pain General health perceptions Vitality Social functioning Limitations in usual activities because of emotional problems	5–10	Yes, HD and PD	Yes	RAND corporation http://www.rand.org/health/surveys_tools.html
SIP	General mental health Physical—ambulation, body care Psychosocial—alertness, emotional behavior, social interactions Independence—sleep, eating, work, recreation	20–30	Yes HD and PD	No	Medical Outcomes Trust http://www.outcomes-trust.org
NHP	Physical mobility Pain Social isolation Emotional reactions Energy Sleep	10–15	No	Yes	
KDQOL- SF	Eight generic domains used in SF-36 Overall health rating Eleven ESRD-related domains: symptoms, effects of kidney disease, burden of kidney disease, work status, cognitive function, quality of social interaction, sexual function, sleep, social support, dialysis staff encouragement, patient satisfaction	20–30	Yes HD only	No	KDQOL working group http://www.gim.med.ucla.edu/kdqol/
CHEP	Eight generic domains used in SF-36 Eight other generic domains: cognitive function, sexual function, sleep, work, recreation, travel, finances, general quality of life Five ESRD-related domains: diet, freedom, body image, dialysis access, symptoms	25	Yes HD and PD	No	

HD, hemodialysis; PD, peritoneal dialysis; SF-36, Short Form 36; SIP, Sickness Impact Profile; NHP, Nottingham Health Profile; KDQOL-SF, Kidney Disease Quality of Life Short-Form; CHEP, CHOICE Health Experience Questionnaire.

assessment. Some common assessments are summarized in Table 1.^{2,3}

By far the most frequently used generic QOL assessment is the Medical Outcomes Study (MOS) 36-item Short Form Health Survey (SF-36).⁴ The assessment takes approximately 5 to 10 min to complete and captures information about the individual's overall health in eight domains.⁵ All domains in the SF-36 are scored from 0 to 100, with higher scores indicating higher QOL. The scores are compared with a standardized norm in a defined population, such as the US general population. There are shorter versions of the SF-36 known as the SF-12 and SF-20, which take 1 to 2 min to administer but are used less often. The SF-36 has been validated in the ESKD population and in general elderly populations. The Sickness Impact Profile (SIP) and Nottingham Health Profile (NHP) are two other commonly used generic assessment tools.

There are also several kidney disease-specific HRQOL instruments available. The Kidney Disease Quality of Life (KDQOL) instruments were initially developed to evaluate the impact of erythropoietin in hemodialysis patients. The first assessment, called KDQOL-long form (LF) included 134 questions that spanned 11 kidney disease targeted scales. In response to criticisms of the KDQOL-LF that it was overly long and redundant, the KDQOL-SF (short form) was released. This test includes questions from the SF-36 plus an additional 43 kidney disease-specific items. A shorter version of this instrument, known as the KDQOL-36 is also available, which contains the same items as in the generic SF-12 along with an additional 24 questions that are kidney disease specific. Some recommend the KDQOL-36 as the preferred measurement tool for large-scale assessments in dialysis facilities because of its ease of administration with relatively minimal patient and staff burden.⁶ The Choices for Healthy Outcomes in Caring for ESKD (CHOICE) Health Experience Questionnaire (CHEP) is another HRQOL assessment that, unlike the KDQOL instruments, was designed for both hemodialysis and peritoneal dialysis populations.

FUNCTIONAL STATUS

Functional status refers to the ability to perform daily activities required to meet basic self-care needs and to maintain health and well being. Functional status reflects both functional capacity, what an individual is capable of doing, and functional performance, what an individual actually does in daily life. Functional status may be affected by impairments in physical, cognitive, sensory, or social function. For example, impairments in physical function, (*e.g.*, muscle strength) or in sensory function (*e.g.*, balance) may both result in difficulty in walking.

METHODS TO ASSESS FUNCTIONAL STATUS

The Karnofsky Performance Status (KPS) was developed to measure functional status in terminally ill patients, and in particular, those with cancer, but has been used in many other chronic illnesses including ESKD (Table 2).⁵⁻⁹ Patients are assigned a score ranging from 0 (dead) to 100 (perfect health).⁷ The scores are usually assigned by the clinician or interviewer. The scale is easy to use but does not detect early changes in functional status. The Katz Activities of Daily Living (ADL) scale was developed to measure functional status in the elderly and in those with chronic disease (Table 3).⁸ The observer determines the level of independence on a three-point scale ranging from independent to dependent in each of the following six activities: bathing, dressing, toileting, transferring, continence, and feeding. It was initially designed for use by direct observation over a period of weeks but has been adapted for use in an interview setting. Because it was used to identify impairments in basic skills, it may be most useful in populations with pre-existing impairments (such as a nursing home setting) or to identify care needs after acute events such as hospitalization. The Lawton Brody Instrumental Activities of Daily Living (IADL) scale was developed to assess performance in everyday tasks among community-dwelling elderly and is commonly

Table 2. Karnofsky Performance Status scale

Description	Score	
Normal no complaints; no evidence of disease.	100	Able to carry on normal activity and to work;
Able to carry on normal activity; minor signs or symptoms of disease.	90	no special care needed
Normal activity with effort; some signs or symptoms of disease.	80	
Cares for self; unable to carry on normal activity or to do active work.	70	Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed
Requires occasional assistance, but is able to care for most of his personal needs.	60	
Requires considerable assistance and frequent medical care.	50	
Disabled; requires special care and assistance	40	Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly
Severely disabled; hospital admission is indicated although death not imminent.	30	
Very sick; hospital admission necessary; active supportive treatment necessary.	20	
Moribund; fatal processes progressing rapidly.	10	
Dead	0	

Table 3. Methods to assess functional status

Test	Domains evaluated	Previously used in ESRD	Resources
Karnofsky Performance Status scale	Global assessment of performance status	Yes	See Table 2
Katz's Activities of Daily Living (ADL) scale	Toileting Feeding Dressing Grooming Physical ambulation Bathing	Yes	Society of Hospital Medicine http://www.hospitalmedicine.org
Lawton Brody Instrumental Activities of Daily Living (IADL) scale	Ability to use telephone Shopping Food Preparation Housekeeping Laundry Mode of Transportation Responsibility for Own Medications Ability to Handle Finances	Yes	Society of Hospital Medicine http://www.hospitalmedicine.org
Rosow-Breslau Health scale	Walking half a mile Walking up and down stairs Doing heavy work around house	No	
Nagi scale	Pulling or pushing large objects Stooping, crouching or kneeling Reaching or extending arms Writing or handling small objects	No	

used in conjunction with the ADL scale.⁹ The IADL scale evaluates skills necessary to live independently, including using the telephone, food preparation, handling finances, and taking medications. Compared with Katz's ADL scale, which assesses basic functions, it is probably more sensitive to early changes in functional status. The Rosow-Breslau Health scale was developed to assess functional status in the elderly.¹⁰ The scale assesses ability to perform physical tasks requiring mobility and strength, such as walking half a mile, climbing up stairs, and doing heavy housework. Like the Lawton-Brody scale, it is most appropriate for community-dwelling elderly patients. The Nagi scale evaluates four types of physical activity: pushing or pulling large objects, stooping, crouching, or kneeling, reaching or extending arms above shoulder level, and writing or handling small objects.¹¹ As opposed to the ADL and IADL scales, the latter two methods assess specific physical activities and therefore may be more useful for identifying areas for intervention.

APPLICATIONS IN CLINICAL CARE

Risk Stratification

Both HRQOL and functional status are strong predictors of adverse outcomes among patients with incident and prevalent

ESKD. For example, in one study of >17,000 hemodialysis patients, a 10-point lower physical component summary (PCS) score on the KDQOL-SF was associated with a 25% increased risk of death, similar to the predictive ability of low serum albumin.¹² In another study of 1000 hemodialysis patients, patients with a PCS score below the median (<34) were twice as likely to die as those patients with PCS scores at or above the median.¹³

Information gathered by HRQOL and functional status instruments, combined with other clinical data, can be used to estimate prognosis. For example, in one study of 292 patients starting dialysis, a risk stratification score based on age, functional status, comorbidity, and planned *versus* unplanned dialysis initiation was used to identify groups with low, medium, and high mortality risk.⁷ Another study of 146 octogenarians starting dialysis categorized patients into risk groups based on body mass index, functional status, and early *versus* late referral. Patients with a body mass index ≤ 18 kg/m², a KPS ≤ 40 , and referred <4 mo before starting dialysis had an estimated 83% risk of mortality in the first year, whereas patients meeting none of these criteria had an estimated 1-yr mortality risk as low as 15%.¹⁴

Estimates of prognosis thus facilitate informed decision making and advanced care planning. Ideally, when discussing dialysis decision making, it is useful to provide information

about expected QOL and functional status in addition to survival; however, data are often limited and sometimes conflicting in this area.^{15–17}

Evaluating Treatment Options

Information about expected HRQOL and functional status can be especially important when interventions may have similar efficacy but different effects on HRQOL and/or functional status, such as the choice of dialysis modality. For example, in the CHOICE study, patients on hemodialysis and peritoneal dialysis had similar overall HRQOL after 1 yr; however, hemodialysis patients experienced greater improvements in sleep and physical function domains, whereas peritoneal dialysis patients experienced greater improvements in the finance domain of QOL.¹⁸

Monitoring Disease Course and Response to Therapy

Serial assessment of HRQOL and functional status may be a useful way to monitor disease course and response to therapy, although it should be noted that for many of the measures discussed here, controversy exists over what constitutes a significant change because several measures have not been validated for longitudinal use. Nonetheless, in an elderly patient with advanced CKD, declining HRQOL and/or functional status in the absence of new medical problems may signal the need for initiation of dialysis. Similarly, in situations where prognosis is unclear and a time-limited trial of dialysis is started, declining HRQOL and functional status may prompt consideration of dialysis withdrawal.

Other Applications

HRQOL and functional status assessments have been shown to improve patient–physician communication¹⁹ and can highlight areas of concern that might otherwise be overlooked. For example, understanding a patient’s ability to perform self-care functions might lead to implementation of assistive devices, use of structured rehabilitation programs, or referral to an assisted living setting. There are some data to suggest that use of these assessment methods in clinical practice leads to improvement in patient satisfaction and overall HRQOL without a significant increase in consultation time.²⁰

TAKE HOME POINTS

- Assessment of HRQOL and functional status can have many applications in clinical care of elderly patients: estimating prognosis, evaluating treatment options, monitoring disease and/or therapy, and identifying occult problems
- Tables 1 and 3 list online resources with information on how to access the HRQOL and functional assessment instruments
- Most measures are simple to use and can be performed during a routine clinic visit

DISCLOSURES

None.

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REVIEW QUESTIONS: METHODS TO ASSESS QUALITY OF LIFE AND FUNCTIONAL STATUS AND THEIR APPLICATIONS IN CLINICAL CARE IN ELDERLY PATIENTS WITH CKD

1. Which of the following is true about the Kidney Disease Quality of Life (KDQOL) instrument?
 - a. It includes generic and disease-specific items
 - b. It has been validated in ESKD patients
 - c. It includes questions from the Medical Outcomes Study Short Form Health Survey (SF-36)
 - d. All of the above
2. Which of the following would not be considered a measure of functional status?
 - a. Bathing ability
 - b. Performance of housework
 - c. Handling finances
 - d. Peak oxygen uptake during a treadmill test
3. Which of the following are potential applications of quality-of-life and/or functional status assessment in elderly ESKD patients?
 - a. Evaluating peritoneal dialysis versus hemodialysis as a treatment options
 - b. Identifying areas of vulnerability prior to entry into a rehabilitation program
 - c. Determining the appropriateness of dialysis withdrawal
 - d. All of the above