

The Evidence and Application of Health-Related Quality of Life in Kidney Stone Disease

Learning Objective: At the conclusion of this continuing medical education activity, the participant will be able to define assessments of health-related quality of life, describe the utility of such assessments in patient-centered kidney stone research and implement generic and disease-specific instruments into clinical care for nephrolithiasis.

This AUA Update aligns with the American Board of Urology Module on Calculus, Laparoscopy-Robotics and Upper Tract Obstruction. Additional information on this topic can be found in the AUA Core Curriculum section on Urolithiasis.

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INTRODUCTION

Nephrolithiasis is one of the most common urological pathologies: the prevalence of stone events in the U.S. population is estimated to be 10.6% for men and 7.1% for women.¹ Over the last several decades, there has been an increase in the lifetime risk of developing a symptomatic episode of kidney stones.²⁻⁴ In fact, nephrolithiasis recurrence rates approach 50% in select patient groups.

Despite this burden of disease, most treatment outcomes of nephrolithiasis have focused primarily on stone-free rate. Although this treatment metric is important, it represents a physician-centric rather than a patient-centric view of the disease. To change this paradigm, it is imperative that urological professionals begin to assess the effectiveness of the management of stone disease using patient-reported outcomes (PROs).

PROs are increasingly emphasized in routine clinical practice to assess symptoms, inform treatment decisions, facilitate communication and track outcomes.^{5,6} By assimilating PROs into management decisions, urologists are able to encourage patient engagement and strengthen the shared decision-making process by highlighting the patient perspective regarding symptom severity and treatment response. Furthermore, tracking the natural course of disease in a given subject can be incorporated into personalized medicine algorithms for individualized care. Population norms may also provide patients with an understanding of the pathological process and standard with which to compare their experiences with the disease.⁵

One such PRO that holds promise for assessment in nephrolithiasis is health-related quality of life (HRQOL), which is a multidimensional construct of how illness and treatment may affect an individual's mental, physical and social well-being.⁷ Measuring HRQOL is particularly relevant in patients with stone disease due to the wide spectrum of disease activity observed over time, which may not correlate with traditional objective indices such as stone-free status on imaging.⁸

Currently, both the American Urological Association and European Association of Urology guidelines consider stone size, location, obstruction and failed response to medical or expectant management as indications for more invasive surgical therapy, but neither guideline incorporates any measures of HRQOL to guide treatment decisions.⁹ In this Update we synthesize the contemporary data to assist with understanding how to capture HRQOL using validated instruments, how HRQOL changes across the disease phases (acute and quiescent) and how HRQOL may be used to guide therapy decisions.

HRQOL BASICS

HRQOL is a general term that considers a patient's duration of life, impairments, functional states, perceptions and social opportunities in relation to their health status.¹⁰ Each of these can be affected by disease states, and an assessment of the

aforementioned categories provides insight into general well-being.

Generic instruments allow for broad evaluation of HRQOL outcomes that are easily comparable across varying degrees of disease and diverse pathologies. These assessment tools have low content validity, as they may contain vague items not relevant to all of those with the disease, but usually have high test-retest and internal consistency and reliability.¹¹ **Disease-specific instruments are utilized to evaluate specific populations, usually with a common diagnosis, often detecting subtle, yet clinically significant changes in HRQOL categories. These generally have higher content validity as assessment questions are tailored to a narrowed disease state, yet they can have lower test-retest and internal consistency as a subject moves through the different phases of their disease.**¹¹ When assessing HRQOL in patient populations, clinicians often use a mixture of generic and disease-specific tools, creating hybrids such as modified generic, generic with disease-specific supplements and batteries of specific measures.¹¹

Assessment of HRQOL can also be conducted through the use of either a profile or preference measure. A profile measure focuses on the reported health status of an individual (descriptive), often assessing one or multiple dimensions of HRQOL, such as pain intensity or social impact. However, a preference measure (evaluative) focuses on the evaluation of the health status of an individual, which provides an overall judgment or an estimate of the value of that health status, often rating it from 0–100 (death to life).^{7,12}

OVERVIEW OF HRQOL INSTRUMENTS

HRQOL can be assessed either with a generic or a disease-specific instrument (table 1). The most widely used generic instrument is the Short Form 36-Item Survey (SF-36).⁵ As a health profile, the SF-36 measures 8 domains, which can be combined into a physical and mental composite summary score.¹² These composite summary scores can be compared to population-based norms. The instrument has excellent reliability and validity with minimal administrative burden (ie time and effort to both take and score the instrument).¹²

There are several other generic instruments, which may demonstrate superior measurement characteristics. For example, the EQ-5D is a preference-based measure, which allows the respondent to generate a health profile across 5 domains and then assign a preference value or utility to their overall health status at that point in time using a visual analogue scale.¹² This measure has demonstrated success in several disease states.¹³

More recently, a robust set of generic PRO instruments was developed through a partnership of U.S. academic institutions and the National Institutes of Health.¹⁴ **The purpose of the Patient-Reported Outcomes Measurement Information System® (PROMIS®) was to provide an item bank of precise, efficient and flexible PRO instruments.**¹⁴ **Several PRO instruments covering diverse domains, such as physical functioning, fatigue, pain, sleep disturbance, emotional distress and social health, were developed.**¹⁴ A major advantage of PROMIS is that scores can be benchmarked to population-based norms

ABBREVIATIONS: HRQOL=health-related quality of life, POD=postoperative day, PRO=patient-reported outcome, PROMIS®=Patient-Reported Outcomes Measurement Information System®, SF-36=Short Form 36-Item Survey, WISQOL=Wisconsin Stone Quality of Life Questionnaire

and computer adaptive testing can be used to significantly reduce the administrative burden.¹⁴ These measures are growing in popularity, particularly within the surgical disciplines, likely due to their flexibility and ease of use.¹⁵ Further increasing their utility, particularly in diseases with a relatively short acute phase such as nephrolithiasis, PROMIS instruments have a 7-day recall period, which may allow stratification of HRQOL at specific treatment time points, such as pre-, intra- and post-operatively.

Previously, only generic instruments were available for nephrolithiasis. A disease-specific HRQOL instrument, the Wisconsin Stone Quality of Life Questionnaire (WISQOL), was developed in 2012, validated in 2016 and publicly released in 2017.^{16,17} **The value of a disease-specific instrument is that it includes dimensions relevant to patients with kidney stones, such as urinary symptoms, which are absent from generic instruments. A disadvantage of the WISQOL is that it was only validated in a single cohort, it is unclear if it is responsive (ie detects clinically meaningful change in HRQOL relative to changes in the disease), it has a high administrative burden and no population-based norms exist.^{16,17} Despite these limitations, it remains the only available disease-specific instrument.**

Although the WISQOL is the only disease-specific instrument, a complementary instrument for assessment of ureteral stent symptomatology does exist and may be applicable for use in individuals with nephrolithiasis undergoing treatment with an indwelling ureteral stent. The Ureteral Stent Symptom Questionnaire is an 11-item instrument that assess the domains of urinary symptoms, bodily pain, general health, work performance, sexual matters and additional problems. It does have reasonable internal consistency, responsiveness and reliability, which makes it an attractive option for assessing the impact of a ureteral stent on HRQOL, although it is not specific for use in the nephrolithiasis population and thus will not be discussed further.¹⁸

ACUTE PHASE (SYMPTOMATIC)

Unfortunately, very little information exists regarding changes in HRQOL during the acute, symptomatic phase of nephrolithiasis, as the majority of prior studies were cross-sectional with instrument administration not timed with the various phases of the disease.

In one of the largest and only available studies examining the acute phase of the disease, Borofsky et al followed a population of over 2,018 patients divided into 4 cohorts based on their type of outpatient encounter: emergency department followup, trial of passage, stent removal and 1-month postoperative visit.¹⁹ At each encounter, pain-specific PROMIS measures (pain interference and pain intensity) were administered. Pain intensity quantifies the amount of pain experienced, while pain interference quantifies the extent to which pain impacts the ability to perform daily activities.

Within the emergency department followup cohort, 83% of patients had severe pain interference scores (defined as a T-score greater than 60), while only 24% of patients had severe pain intensity scores. In the post-stent removal cohort, 57% of patients reported severe pain interference and only 8% reported severe pain intensity. Similarly, only 38% and 4% of patients reported severe pain interference within the trial of passage and 1-month postoperative cohorts, respectively. In both of these cohorts, less than 5% of patients had severe

pain intensity scores. All of the pain scores varied significantly between each cohort.¹⁹

The emergency department followup cohort had the worst HRQOL, followed by the ureteral stent removal group. **However, in each cohort, the number of patients reporting severe pain interference scores was significantly greater than the number of patients reporting severe pain intensity scores.¹⁹ This demonstrates that pain interference is more responsive than intensity, or that simply assessing pain in the traditional sense (intensity, 0–10 scale) is a poor measure of the impact of nephrolithiasis on HRQOL, particularly during the acute or perioperative phase of the disease. Furthermore, assessing impact on daily activities (in this case, the impact of pain) may be more a meaningful outcome.**

In another assessment of HRQOL for those undergoing a trial of passage with medical expulsive therapy, often the initial pathway, a recent large randomized prospective trial examining the effectiveness of tamsulosin, nifedipine and placebo in facilitating ureteral stone passage found no difference between these groups in the physical or mental summary component score of the SF-36.²⁰ This held true across all time points, including at enrollment, and 4 and 12 weeks. This study suggests that an acute ureteral stone managed with a trial of passage with medical expulsive therapy has limited impact on HRQOL at least relative to the use of no medication to facilitate passage.²⁰ However, it is possible this null finding is a result of using the SF-36, which may not be sensitive enough, particularly when only including the composite summary scores for detecting change related to acute ureteral stone symptomatology. This highlights the importance of identifying and then assessing HRQOL domains that are important to patients with the disease, rather than using metrics assigned by the research or clinical team, or in this case, relying only on generic HRQOL instruments, like the SF-36.

QUIESCENT PHASE (ASYMPTOMATIC)

Initial studies in the assessment of HRQOL in patients with nephrolithiasis did not differentiate between symptomatic and asymptomatic phases of disease, and thus most patients were assessed during the quiescent state. The first study utilizing the SF-36 assessed generic HRQOL in 189 stone formers. Penniston and Nakada found that patients with nephrolithiasis had significantly lower quality of life in 2 domains, general health and bodily pain, while the other 6 domains remained comparable to U.S. population means.²¹ Furthermore, women with nephrolithiasis were found to have lower scores for all domains except social functioning as compared to their male counterparts. Underlying comorbidities such as depression, hypertension, diabetes and obesity were also associated with lower scores across multiple domains. Interestingly, both number of stone surgeries and extracorporeal shock wave lithotripsy had no correlation with change in HRQOL.²¹ However, the retrospective, cross-sectional study design as a single assessment of SF-36, as well as a lack of categorization by phase of disease (acute, chronic etc), were notable limitations.²¹

Similarly, Bensalah et al performed a cross-sectional survey in 155 stone formers, also using the SF-36, and demonstrated lower physical functioning, role physical, general health, and social functioning scores as compared to standardized population means.²² However, unlike the initial study by Penniston and Nakada, they measured time from a renal colic event and deter-

mined that proximity to the acute exacerbation was associated with lower scores in the physical composite, bodily pain, general health and social functioning domains. Additionally, another difference noted was the decline in HRQOL correlated with number of surgeries and ureteral stent placement.²²

A prospective assessment was then performed, with a median followup time of 18 months.²³ Of the patients who did not report an acute stone event during the month leading up to either the enrollment or followup survey, no difference in SF-36 scores was noted in any domain. In the cohort of patients who reported a stone event in the preceding month prior to the initial but not the subsequent survey administration, there was still no difference in scores within any HRQOL domain.²³ **Thus, the authors concluded that the SF-36 may not be responsive enough to detect changes in quality of life scores in the nephrolithiasis population, highlighting the utility of a disease-specific instrument.**

This was ultimately the impetus for the development of the WISQOL, which is the only disease-specific instrument for nephrolithiasis. In the initial development of the instrument, 89% of WISQOL items had varying responses between patients with and without nephrolithiasis, whereas only 19% of SF-36 items had varying responses between these same patient populations. **Therefore, the creators suggest that WISQOL has the ability to detect stone-specific HRQOL detriments.¹⁷ Through validation of the WISQOL survey, the creators found that patients with stones and related symptoms scored lower than those with asymptomatic stones or no stones.¹⁷**

Symptomatic stone formers have been found to have HRQOL deficits on both generic and disease-specific instruments. **However, even asymptomatic patients with urolithiasis have been shown to have decrements in specific HRQOL domains.** In a study by Penniston et al, the authors administered the WISQOL survey to 107 patients with no stone-related complaints at the time of the encounter, 78% of whom were recurrent stone formers who had either passed a stone or required a surgical intervention.⁸ Self-perception of stone status was assessed and confirmed by imaging (kidney, ureter and bladder x-ray, computerized tomography or ultrasound). Of the 49% of patients who believed they had stones, 82% were correct. **Patients who had perceived positive stone status were significantly more bothered by urinary frequency than those who did not believe they had stones at the time of survey administration. Regardless of perception, patients who were confirmed to have stones on imaging reported significantly higher rates of urinary urgency and anxiety about the future than those without stones.⁸ Therefore, even patients in the asymptomatic phase of disease may have HRQOL impairments.**

Utilizing WISQOL, Ahmad et al evaluated how self-reported race and socioeconomic status affected HRQOL scores in approximately 2,000 patients.²⁴ **Lower income, nonwhite and unemployed patients had significantly lower scores, particularly in regard to the symptom and social domains.** The effects associated with race were independent of income level, which is notable given that the link between race and health care disparities is often thought to be confounded by socioeconomic status.²⁴ Stern et al also used WISQOL in a sample of 1,240 stone formers, and found that both gender and age were associated with HRQOL.²⁵ **Men had higher scores in social function,**

stone-related impact and vitality domains, while older patients had higher scores across all domains. Thus, demographic factors may play a specific role in the lived experience of nephrolithiasis, even outside the acute phase of disease.

The WISQOL is also capable of detecting differences in HRQOL for stone patients on preventive medical therapy. **Raffin et al designed a cross-sectional study with 1,511 participants that found statistically significant higher HRQOL scores for patients undergoing treatment with either thiazide diuretics or potassium citrate when compared to patients without ongoing medical management for their nephrolithiasis.²⁶** This held true across all 4 domains of the survey, including after adjustment with multivariable analyses.²⁶ However, the cross-sectional nature of the study was again a notable limitation.

POSTOPERATIVE

Although surgical therapy for nephrolithiasis is common, traditional outcomes have focused largely on objective measures such as stone-free rate and not patient-centric measures such as HRQOL. As a result, very limited data exist to help guide urologists and patients alike in terms of the impact of surgery on HRQOL and expectations of recovery of HRQOL.

In one of the only prospective studies examining HRQOL following ureteroscopy, Talwar et al followed 126 patients at baseline and 1, 7 and 14 days after surgery with repeated measures of PROMIS Pain Intensity and Interference (similar to the Borofsky et al study). Not surprisingly, pain intensity scores were lower than the U.S. population mean preoperatively on postoperative day (POD) 0, were higher than the mean on POD 1, improved to below the mean on POD 7 and remained below the mean on POD 14.⁶ These changes were all clinically significant. However, unlike pain intensity, there was a delay in improvement in pain interference. Pain interference remained elevated compared to U.S. population means on POD 0, 1 and 7, only improving and returning below the mean on assessment on POD 14 (1 week later than pain intensity). Again, all of these changes were clinically significant. Only increasing age was predictive of lower pain intensity and interference scores on POD 1, and not any operative characteristic, including ureteral stent placement.⁶

This information suggests that ureteroscopy is a painful therapy, impacting both pain intensity and interference (ie disruption of daily activities due to pain). Interference is significantly more degraded. It also highlights the pattern and time to recovery, which is approximately 1 week for intensity, although longer for interference at 2 weeks.⁶ In both cases, there was degradation of these domains past the dwell time for the ureteral stent. Interestingly, the distribution of the scores at each time point and for each domain was quite large, suggesting that there is not uniform recovery, but that it is highly variable.⁶ These data help to guide expectation setting with regard to recovery after ureteroscopy.

The tolerability of different types of postoperative drainage following surgical intervention has also been studied. In a prospective randomized study on different drainage approaches after percutaneous nephrolithotomy, 90 patients were randomized to 18Fr nephrostomy tube, 5Fr ureteral stent or 5Fr open-ended ureteral catheter attached to a Foley catheter.²⁷ Changes in the WISQOL domains were measured by comparing POD 14 values to preoperative values. Patients who underwent ureteral stent placement reported significantly higher rates of

stent irritation-related symptoms, such as nocturia, frequency and urgency. They were also found to have higher rates of anxiety, annoyance and irritability, and lower motivation, interest in sex and socializing. Only 70% of patients in this ureteral stent cohort indicated they would undergo the same procedure in the future, compared to rates of 86.7% and 96.7% in the nephrostomy tube and ureteral catheter cohorts, respectively.²⁷ If only focusing on the stone-free rate, all 3 interventions would demonstrate clinically insignificant differences; however, HRQOL during the postoperative recovery period was quite variable.

APPLICATIONS

It is clear from the emerging body of evidence that nephrolithiasis impacts HRQOL (table 2). However, who is the most affected, what conditions are they affected under and what domains are impacted are among the many questions that are yet to be studied and answered. This is, at least in part, due to the lack of high quality rigorous trials in nephrolithiasis that focus on HRQOL outcomes. However, this paradigm is slowly changing.

The NIDDK (National Institute of Diabetes and Digestive and Kidney Diseases) Urinary Stone Disease Research Network has funded a prospective observational cohort study (STENTS) to examine stent-associated symptoms after ureteroscopy in adolescents and adults.²⁸ The focus on PROs is a novel aspect of this study—specifically several HRQOL domains theorized to be degraded with an indwelling ureteral stent—including anxiety, catastrophizing, depression, stress, somatic symptoms, urinary symptoms, and pain intensity and interference. It is expected that this trial will help elucidate certainly who but also potentially why certain individuals develop such severe and debilitating symptoms related to a urinary stent.²⁸ With this information, it may be feasible for urologists to finally predict those individuals most at risk for stent symptoms, and thus appropriately modify surgery to eliminate an indwelling stent or develop additional therapies to lessen the impact in those who do require a ureteral stent.

Similar to the NIDDK funded STENTS study in adolescents and adults, the Pediatric KIDney Stone (PKIDS) Care Improvement Network, a collection of 26 pediatric health care systems throughout North America, is currently engaged in a PCORI (Patient-Centered Outcomes Research Institute)-funded prospective study comparing stone clearance and lived experience after surgery for the pediatric kidney stone population. Again, this investigation focuses on PROs, which include dysfunctional voiding and urinary symptoms, anxiety, peer relationships, stress, sleep disturbance, medication misuse, and pain intensity and interference. However, unlike the prior STENTS study, these domains were all selected based on input directly from children with nephrolithiasis and their caregivers. By prioritizing the outcomes most meaningful to those with the disease, it will eventually be possible to use these results to more comprehensively counsel patients regarding the anticipated outcomes and thus accurately select individualized interventions for nephrolithiasis.

Although the above trials provide an example of the movement toward incorporating the assessment of HRQOL in nephrolithiasis research, the application of it to clinical practice remains in its infancy. Yet, there is significant promise and potential. For example, at the individual level it is possible

to use a HRQOL instrument to screen for new diseases or conditions, assess disease severity, identify the most appropriate treatment, track response to therapy and set personalized outcome goals.²⁹ In fact, we already see this to some degree within the urological profession with the use of the American Urological Association Symptom Score or International Prostate Symptom Score to screen, diagnosis and assess outcomes related to therapy for lower urinary tract symptoms.^{30,31} **A similar application of HRQOL instruments to the nephrolithiasis population could be of equal value, particularly in monitoring for recovery during the immediate postoperative period or for identifying new symptoms/stones during the quiescent/chronic phase of the disease.**

However, several measurement and logistical issues should be taken into consideration as we begin to apply HRQOL to clinical practice (see figure).²⁹ **First, does the instrument being considered have meaning or value to the patient in the context of their disease?** This is why selecting patient-prioritized rather than clinician-selected instruments is ideal. **Second, does the instrument provide for assessment**

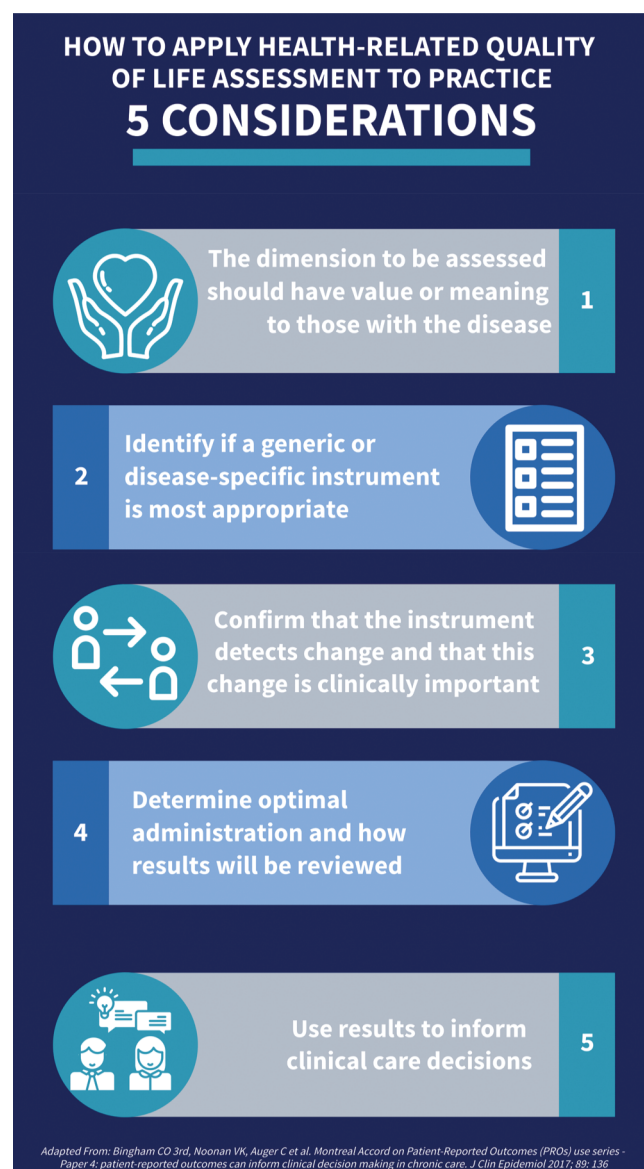


Figure. Applying HRQOL assessment to practice.

of disease-specific or generic symptoms? For example, the WISQOL is a disease-specific instrument and includes domains such as urinary frequency and fear of travel unique to those with nephrolithiasis, while a generic instrument like the SF-36 does not.¹⁷ However, each instrument has its value in the appropriate clinical context. **Third, will it detect a change, and is that change meaningful or clinically important?** For the results to be useful, there needs to be a difference both between and within an individual in response to changes in the disease or treatment. **Fourth, how long does it take for the patient to complete it, and how is this information transmitted to and reviewed by the clinical team?** A longer instrument will invariably lead to lower completion rates. However, integration of the instruments into the electronic health record or patient portal allows this process to be done electronically and asynchronously, easing data capture and review.³² The PROMIS measures already have this capability (<https://www.healthmeasures.net/explore-measurement-systems/>). In addition, short-form versions exist for many of the PROMIS measures as well as for the SF-36. For example, the SF-12 only contains 12 items, provides excellent correlation to the SF-36 physical and mental composite summary scores, and takes 2 minutes or less for self-administration.³³ These short-forms are ideal for use in the busy clinical setting. **Fifth, and arguably the most important, how is this information used to change clinical care or treatment decisions?** Incorporating all of this into the context of a larger shared decision-making conversation will be critical to optimizing outcomes. This is also where the impact of preference measures can be quite profound by determining the relative value or utility of the health state following competing treatment modalities (such as ureteroscopy and shock wave lithotripsy), ultimately determining which may have the greatest impact on quality-adjusted time.

By taking these considerations into account, it will be possible to capitalize on the promise of assessing and utilizing HRQOL in the clinical care of nephrolithiasis.^{6,19} Moving forward, it will be up to urological professionals to begin to identify how best to incorporate these tools into their local practices and leverage the information to improve satisfaction and outcomes for patients with nephrolithiasis.

CONCLUSION

HRQOL is a multidimensional construction of how disease affects one's well-being. It can be measured with both disease-specific and generic instruments. Initially, generic instruments revealed decreased HRQOL in patients with nephrolithiasis as compared to population-based norms. Recently, a disease-specific tool was developed and has provided more insight into the specific symptoms that negatively affect the patient experience, such as urinary symptoms. It is clear, regardless of type of measure, that HRQOL is degraded across the acute, postoperative and quiescent phases of the disease. Incorporation of HRQOL into clinical trials of surgical therapy will undoubtedly reveal interesting HRQOL phenotypes and provide vital information that will help guide preoperative counseling and treatment selection. There is also significant promise for use of HRQOL in routine clinical practice to aid in the diagnosis of new symptoms that could signify new metabolic activity or stone formation, track recovery after surgical intervention and individualize treatment plans during prevention or observation. By standardizing the incorporation of HRQOL measures into our research and clinical decision-making, we have the opportunity to improve the health care experience for our patients.

DID YOU KNOW?

- Health-related quality of life is an important consideration in nephrolithiasis given that individual patients experience the disease process differently.
- Stone formers exhibit detriments in health-related quality of life during acute and quiescent phases of nephrolithiasis.
- Preoperative and postoperative assessments can be useful in longitudinally tracking a patient's progression throughout various phases of treatment.
- Future research will allow urologists to identify predictors of poor health-related quality of life and tailor specific interventions accordingly.

Table 1. HRQOL instruments in use for nephrolithiasis

Instrument Name	Instrument Type	Measured Domains	Instrument Source
SF-36	Generic instrument	Physical functioning Role limitations due to physical health Role limitations due to emotional problems Energy/fatigue Emotional well-being Social functioning General health Pain	https://www.rand.org/health/surveys_tools/mos/36-item-short-form.html
PROMIS®-29 Profile (v2.0)	Generic instrument	Physical function Anxiety Depression Fatigue Sleep disturbance Participate in social roles/activities Pain interference Pain intensity	http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
WISQOL	Disease-specific instrument	Social impact Emotional impact Disease impact Vitality impact Total	https://www.urology.wisc.edu/wisqol

Table 2. Summary of seminal HRQOL outcomes in nephrolithiasis

Author(s), Year	Instrument Used	Population	Primary Outcome
Penniston and Nakada, 2007 ²¹	SF-36	189 Patients with nephrolithiasis	HRQOL detriments noted in general health and bodily pain domains
Bensalah et al, 2008 ²²	SF-36	155 Patients with nephrolithiasis	HRQOL detriments noted in domains of physical functioning, role physical, general health, social functioning
Donnally et al, 2011 ²³	SF-36	152 Patients with nephrolithiasis evaluated in the outpatient setting	No differences in HRQOL between baseline and followup visits, or baseline and those who had a stone event in the prior month
Penniston and Nakada, 2013 ¹⁷	WISQOL	248 Patients with nephrolithiasis evaluated in the outpatient setting	Described a disease-specific tool for detecting HRQOL detriments in stone formers
Penniston et al, 2016 ⁸	WISQOL	107 Asymptomatic patients with a history of nephrolithiasis	HRQOL detriments found in patients who perceived they had active stone disease (regardless of confirmation via imaging) and those who were confirmed to have active disease
Jiang et al, 2017 ²⁷	WISQOL	90 Patients undergoing percutaneous nephrolithotomy randomized to postoperative drainage by nephrostomy tube, ureteral stent or ureteral catheter	Decreased HRQOL in patients who underwent ureteral stent drainage after percutaneous nephrolithotomy versus nephrostomy tube or ureteral catheter
Borofsky et al, 2017 ¹⁹	PROMIS	1,162 Patients with nephrolithiasis	Decreased pain interference scores in patients after emergency room encounter, ureteral stent removal and trial of passage

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Study Questions Volume 40 Lesson 31

1. Generic health-related quality of life instruments can be used in specific disease states. However, a significant weakness is that they may
 - a. lack sensitivity to detect subtle differences
 - b. have low internal consistency and reliability
 - c. not allow population level mean comparisons
 - d. not be easily comparable between different disease states
2. Disease-specific health-related quality of life instruments are valuable given that they generally
 - a. allow population level mean comparisons
 - b. have sensitivity to detect subtle differences
 - c. have high internal consistency and reliability
 - d. are easily comparable between different disease states
3. The Patient-Reported Outcomes Measurement Information System (PROMIS) as a set of quality of life assessment instruments is
 - a. disease-specific
 - b. imprecise
 - c. inefficient
 - d. flexible
4. During the acute and postoperative phases of kidney stone disease, the impact of pain is described as
 - a. only pain intensity is worse
 - b. only pain interference is worse
 - c. both pain intensity and interference are worse
 - d. neither pain intensity nor interference is impacted
5. During the quiescent phase of kidney stone disease, it appears that even relatively asymptomatic stone formers continue to have health-related quality of life changes consisting of
 - a. decreased health-related quality of life while on preventive medication
 - b. increased urinary frequency
 - c. no change in pain intensity
 - d. decreased anxiety