Purpose of review
The objective of this article is to address patients’ expectations of stone treatment – both surgical and medical – and their health-related quality of life (HRQOL). We present a rationale for greater inclusion of measures to assess patient expectations, satisfaction, and HRQOL into surgical and medical management for patients with recurrent urolithiasis.

Recent findings
Patients’ treatment expectations and HRQOL are fundamental and progressive new areas of interest in urolithiasis. Patients whose treatment regimens result in outcomes that match their expectations are likely to be more satisfied, which may influence their HRQOL, a valid and valuable outcome of any medical treatment or procedure. Patient perceptions of treatment effects for stones, whether surgical or medical, are complex and may not reflect only stone-free rates, surgical complication rates, and side-effects, the outcomes of traditional interest in urology.

Summary
If we understand the issues of most importance to our patients, we can provide appropriate information and education that ensures the most realistic expectations, minimizes disappointment and risk, and contributes most to the patients’ HRQOL.

Keywords
health-related quality of life, patient expectations, patient preferences, patient satisfaction, treatment expectations

INTRODUCTION
At multiple points along the disease continuum, the health-related quality of life (HRQOL) of patients who form kidney stones is reduced [1–6]. Although genetic, anatomic, pharmacologic, and comorbid influences on urolithiasis exist, there are nonetheless modifiable risk factors. Appropriate attention to these factors could reduce recurrence, reducing the need for repeated surgical interventions, which may contribute to improvements in HRQOL [8,9,10]. Many patients who form kidney stones express a desire for prevention [11] and reduced surgical procedures [12], despite the development in recent decades of minimally invasive stone removal. A component of HRQOL is how well patients’ expectations of treatment match with their perceived results. If expectations for a specific therapy are high and the perceived value of the outcome is also high, patients are satisfied. Satisfaction with health status, whatever that may be, contributes significantly to HRQOL. On the contrary, if high expectations are followed by outcomes that are perceived as suboptimal or inferior, satisfaction is likely to be lower with concomitant impact on HRQOL.

IMPACT OF UROLITHIASIS ON PATIENTS
Urolithiasis is a benign urologic condition for which there is usually no cure. It is frequently recurrent (i.e. chronic), with episodes of acute or intermittent pain lasting for hours, days, or weeks followed by periods of quiescence. The movement of a stone...
KEY POINTS

- Many patients with recurrent kidney stones express a desire for prevention and reduced surgical procedures, in contrast to many urologists’ perceptions and despite the development in recent decades of minimally invasive stone removal.

- Although the field of urology has historically been focused primarily on improving results, reforms in healthcare delivery will require greater attention placed on patient-reported outcomes such as satisfaction, treatment expectations, and quality of life.

- Patient expectations and perceptions of stone treatments, whether surgical or medical, are complex and may not reflect only stone-free-rates, surgical complication rates, and side-effects, the traditional outcomes of interest in urology.

- The use of patient-reported outcomes in stone management, with implementation of changes in current practices as needed, may further our knowledge of the pathophysiology and burden of urolithiasis and increase the overall value of care.

UROLITHIASIS AND TREATMENT EXPECTATIONS

Treatment expectations remain a complex matter amplified by a report in which patients on chemotherapy for metastatic disease incorrectly thought the treatment was curative [16]. In a similar fashion, treatment decisions for patients with kidney stones are a vexing issue at this point in time because of the variety of treatments available for the most common stone types. Although percutaneous nephrolithotripsy is typically required for larger renal and staghorn stones, this procedure is typically well delineated and requires referral in many instances to a large center for management. In these scenarios, the choice of approach has already been made, and treatment expectations are directed clearly at the surgeon’s experience, which should be substantial, as is the case in most referral centers.

On the contrary, smaller renal and ureteral stones can be managed conservatively, with medical expulsive therapy (MET), ureteroscopically (URS), or with shockwave lithotripsy (SWL). These are different treatments, and patients may have a different treatment expectation with each, which will quickly add to the complexity of decision-making. Moreover, factors such as stone-free rates, pain, cost, and radiation exposure all lead to a complex matrix of outcomes and considerations to manage.

Bensalah et al. [12] demonstrated that physician expectations for patients were quite disparate from patient desires regarding stone treatment, specifically as it relates to the desire to undergo procedures seeking stone-free status. Moreover, Chandrasekar [17**] queried patients who had undergone stone surgery as to their preferences and relative satisfaction with procedures. The majority of patients reported being satisfied or very satisfied with their treatment choice, even when treatment was SWL, which is associated with the need for more secondary procedures than URS. This is intriguing when current evidence reveals an increasing use of URS in the USA [18].

We are currently in an era in which patient choice and shared decision-making are peaking in interest. Both Kouriefs and Quatan conducted studies that revealed unclear and perhaps unreasonable patient expectations regarding stone clearance following SWL. More importantly, these same authors were surprised as stone clearance was rated as more important than pain control by their patients [19,20], thus indicating an alternate view to that of the urologist.

Rippel et al. [21] reported a 38% residual fragment rate following URS. Of note, these were experienced urologists with high skill levels, but with the aid of computed tomography scan as the main imaging modality, these data were presented to ‘reset’ patient expectations. One may ask how much resetting is necessary. If greater efforts were made to summarize the available evidence for patients, describe the tools of the procedures, and provide salient guidance, perhaps this would avoid contributing to expectations that may in fact be unrealistic.

As such, Streeper [22] has reported using patient decision-making aids in helping patients select
between various treatment options for smaller stones. This study identified that stone patients preferred receiving more information, beyond that presumed by the authors, and their concerns were focused as much on side-effects and pain as stone-free status. In the end, they appreciated most the recommendation of the urologist. In a follow-up study, this group used a multitude of patient decision-making aids in clinic patients and further validated the principle that patients preferred more active decision-making and, most importantly, clearer expectations [23].

What about patients’ expectations for medical management? Little attention has been placed on this. But as both dietary and medication regimens can be complex and involve multiple changes to daily routines, it should be explored further. Moreover, if the promise of a specific dietary change or medication does not result in reduced stone formation – as may be the case because of application of inappropriate therapy or patient noncompliance – what does that do to patients’ expectations of therapy and to their motivation to continue it?

So where is our field, and more importantly, where are our patients when it comes to treatment expectations regarding stone disease? Although the answer to this question is far from precise, it is evident there remains a disconnect. More tangibly, the field appears mostly focused on improving results rather than meeting patients’ expectations or improving their HRQOL. In one sense this is reasonable, as urologists are seeking better outcomes as guided by insurers and government payment plans. But perhaps when it comes to patient satisfaction and HRQOL, we stand to gain the most by better understanding patients’ treatment expectations.

**UROLITHIASIS AND HEALTH-RELATED QUALITY OF LIFE**

The WHO has defined HRQOL as an individual’s perception of his or her health and health-related aspects of well-being [24]. HRQOL is patient-reported, differentiating it from the healthcare practitioner’s objective health assessment of the individual. HRQOL is a subset of the broader term quality of life (QOL), defined by WHO as ‘an individual’s perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ [25]. Health status is one component, perhaps one of the strongest, of global QOL. The concept of HRQOL evolved over time as increased life expectancy, due largely to advances in medical and surgical practices, resulted in an increasing number of people living with chronic disease from which they would previously have died. HRQOL is identified as a goal for all people across all life stages and across all health statuses by public health and other organizations. HRQOL is increasingly appreciated by health policymakers, researchers, and practitioners as one of many outcomes required to assess the true value of healthcare.

HRQOL is dynamic with the potential to change over time because of changes in health status. It is multidimensional, incorporating physical, social, and psychological dimensions. For these reasons, urolithiasis is well suited to inclusion of HRQOL into medical and surgical management. In fact, it may be an example of an ‘ideal’ condition for which patients’ HRQOL should be included in medical and surgical decision-making and in the design of long-term therapeutic regimens. The traditional goal of a ‘cure’, after all, is usually not realistic for patients with recurrent kidney stones, even if medical and surgical management are perfectly executed. Patients’ expectations of treatment and their HRQOL during treatment can be valuable outcome parameters.

**Surgical management for stones**

Unlike other conditions, the goal of surgical therapy for stones is not always to cure. Surgery does not often eliminate the cause(s) for stone formation. Rather, the surgical goal is to remove problematic stone(s) and render the patient free of pain and of the risk for more serious conditions such as renal dysfunction or failure. With the appropriate surgical modality and – if indicated – after prior attempts at active surveillance or MET, stone removal offers necessary palliative treatment. But stone removal does not reduce the risk of future stone formation and does not obviate the need for medical management to address metabolic, genetic, anatomic, or environmental risk factors. In some cases, surgery even fails to render the patient free of stones or fragments. Surgery is expensive and not altogether without patient morbidity, both of which may influence patients’ HRQOL. Finally, ureteral stenting with SWL or URS is well known to reduce patients’ HRQOL [26–28].

Nevertheless, surgical intervention is now a mainstay in the management of recurrent urolithiasis, not only in those with aggressive stone formation and/or with infectious or large obstructive renal stones but also in those with less problematic or even asymptomatic stones. Multiple surgical modalities are currently available, each with its specific indication and utility. Advances in minimally invasive surgical techniques and imaging have moved surgery to the forefront of the stone
treatment/management arsenal. Indeed, a subset of patients with a history of recurrent stones initiating medical management in our clinic report being previously offered only repeated surgery for their recurrent stones— even over a period of years— with no mention of prevention or medical management.

### Incorporating HRQOL in stone surgery

Traditionally, urologists have defined surgical success as stone-free status that is achieved with the most minimal of complications. Presumably, stone removal in patients with symptomatic stones results in improvements in patients’ health and symptoms, yet this has not been a typical endpoint for assessing surgical success and would moreover be difficult to confirm in those who undergo surgery for asymptomatic stones. Information about when surgical intervention should be initiated, if at all, and whether certain procedures result in greater overall value— defined as health outcomes (including patient-centered) achieved per dollar spent [29]— can be obtained by including HRQOL as a surgical outcome measure.

Although there is a substantial body of literature reporting stone-free rates, complications, and the cost effectiveness of various surgical modalities, there is little literature documenting patients’ HRQOL and other patient-reported outcomes after surgery. There has been some interest in patients’ surgical preferences, a clearly patient-centered outcome that may impact patients’ satisfaction with treatment and their HRQOL. But application of this information appears limited. Patients’ surgical preferences, for example, appear weighted toward SWL rather than URS [30–34], yet URS procedures in the USA are significantly higher and increasing [35**]. URS may be more efficient at stone removal and clearance, but is that the only factor that should be considered in assessing surgical success?

Patient satisfaction with surgical intervention is another factor that could be measured and thus warrants more attention. Ghalayini et al. [36] found that patients were more satisfied with surgical procedures that had higher stone clearance. Others, as addressed earlier, have revealed discrepancies with their *a priori* assumptions about what was important to patients and their satisfaction with surgery [19,20], finding that stone clearance is not always most important. In a small study of their patients who had undergone percutaneous nephrolithotomy, Staicos et al. [37] found that HRQOL improved in only half of patients who had been rendered stone free. Clearly other factors influence patient satisfaction. Recent efforts to learn more about patient satisfaction as a surgical outcome are reported [17**,38**]. Knowledge gained from such inquiries could ultimately be applied to surgical decision-making and in assessing surgical success.

### Medical management for stones

Medical management of urolithiasis dates back to antiquity. As surgical options were limited and usually resulted in patient death because of infection or inordinate blood loss from invasive procedures, attempts at first relieving obstruction and pain, inducing expulsion, and prevention are documented [39]. Stone removal was a last resort, the indication for which was captured famously by Celsus (25 BC–50 CE) who urged that stone ‘cutting’ be undertaken only ‘if the disease is so bad that it cannot be relieved by medicaments, or endured by the patient without shortly bringing his life to a close’ [39].

Modern medical management includes pharmacologic and/or dietary interventions that are individualized to each patient’s risk profile. Just as surgery is not a cure for urolithiasis, medical management is also not always curative. As stone formation is largely silent and proceeds sometimes over years, measuring the success of prevention is difficult and thus not well documented. Patients for whom medical management successfully addresses an underlying medical condition (e.g. malabsorption) or in those with environmentally induced stone formation (e.g. dehydration, medication-induced stones) may enjoy remission from stones and, over time, even a cure. However, in most recurrent patients a clear and single cause for stone formation is not discernable. The goal of medical management in these patients is to reduce the acuity and aggressiveness of urolithiasis by reducing the number of stones formed, their size, and their potential for discomfort or harm. Medical management that is appropriately prescribed and implemented is proven to reduce the risk for recurrence and stone recurrence over time. Guidelines for medical management were recently developed by the American Urological Association [40**] and the European Association of Urology [41**].

### Incorporating HRQOL in medical management

Unless medical management corrects or reverses a problem that clearly gave rise to stone formation, it is usually possible to offer only the prediction of reduced risk. Because few studies have assessed the effect of medical management on stone formation over time, the effectiveness of medical management has typically been assessed by comparing
preintervention and postintervention urinary risk factors for stones and with periodic imaging studies to assess formation and growth.

But what about effects on other patient outcomes? Medical management is unlike surgery, which is a one-time event or, even when repeated, is something that patients undergo only intermittently. In contrast, medications and dietary habits must be taken and practiced daily in order to be successful. Although many patients voice a desire for prevention, even if it requires lifelong medication [11], the effect of long-term medical management on patients’ HRQOL is largely unknown. Physical side-effects (gastrointestinal upset, changes in bowel habits, alterations in blood pressure, weakness, dizziness, erectile dysfunction) from thiazides and potassium citrate are reported [42,43]. As many if not most of these symptoms conceivably affect HRQOL, this should be further explored. In addition, variable side-effect profiles by sex have been reported for some medications [44], including those used in medical stone management; this could be a potential factor in the lower HRQOL of female versus male stone formers [1] and warrants more attention.

If implemented, dietary recommendations also require daily attention. But unlike medication, which is usually taken once or perhaps twice daily, people interact with foods multiple times in a day and in multiple social situations and locations. Moreover, in contrast to medication, which is the same every day, people usually eat different foods every day, and there are multiple food choices that could meet a certain dietary recommendation. Reducing intake of high-salt foods, for example, requires knowledge of the many foods that are high salt. Inclusion of calcium-containing foods and beverages at meals to control oxalate absorption requires similar knowledge of the multiple food items available to meet this recommendation. Finally, patients with kidney stones frequently have other medical conditions for which dietary changes have been implemented. Without education and counseling from a dietitian or nutritionist, attempts to integrate dietary stone prevention with other regimens may increase patient frustration and anxiety. Patients with diabetes, for example, may be wary of consuming more citrus fruits (carbohydrate-rich foods) as may be recommended to increase the intake of bicarbonate precursors that could enhance renal citrate excretion.

For these reasons, the burden of nutrition therapy on patients is high and must be sustained on a daily basis, requiring diligence and discipline. As with pharmacologic therapy, few studies have examined the impact of nutrition intervention on patients’ HRQOL. Insights into how dietary changes affect patients’ HRQOL could lead to improved ways of delivering nutrition therapy, perhaps by better prioritizing and customizing dietary recommendations, better explaining the rationale for dietary changes, or providing more patient-friendly strategies for achieving the goals of therapy.

CONCLUSION

There are multiple reasons for measuring patients’ HRQOL [45]. In urolithiasis, HRQOL can serve as an additional tool that urologists and other providers use to further understand the impact of kidney stones on patients. It could therefore complement and add to information not traditionally or previously included in clinical assessment. Measuring HRQOL in our patients could further our understanding of the natural history of urolithiasis. Studying HRQOL could be useful in phenotyping urolithiasis, which could ultimately be used in both forward and reverse genetic approaches aimed at gaining important insights about the pathophysiology of urolithiasis and its treatment. The routine inclusion of HRQOL in our field could enhance our understanding of treatment effects (both surgical and medical) on patients. After all, the goal of therapy of any kind is to improve patients’ lives; measuring patients’ HRQOL can help us determine if we are meeting that goal.

As we gain experience in incorporating patient-reported outcomes such as satisfaction, treatment expectations, and HRQOL, we could learn how to better identify the best choices among alternative options – be they surgical, pharmacological, or nutritional – for our patients. Measuring HRQOL over the course of medical management could help to identify variable side-effects of treatment in certain patient sub-populations and could help to predict response to therapy. Postsurgical HRQOL could be useful to identify patients that require extra attention in rehabilitation and to identify whether certain patients are less suited than others to certain procedures. In summary, knowledge of patients’ HRQOL at all points along medical and surgical management continuums could help guide future patients toward regimens and procedures that have greater expected value, satisfaction, and overall QOL.

Acknowledgements

None.

Financial support and sponsorship

None.

Conflicts of interest

There are no conflicts of interest.
The investigators used the SF-36 to examine patients’ HRQOL after intervention.

Angell J, Bryant M, Tu H, et al.


who had experience with kidney stones to participate. This study demonstrates the limitations of patients based on the size of fragments following intervention.

The investigators follow their previous work by stratifying HRQOL results (from SF-36) of patients who form cystine stones.


The investigators used the SF-36 to examine patients’ HRQOL after intervention.


The investigators follow their previous work by stratifying HRQOL results (from SF-36) of patients based on the size of fragments following intervention.

Penniston and Nakada