



Gaps in kidney stone disease management: From clinical theory to patient reality

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Abstract

With nephrolithiasis projected to affect 25% of the global population in the next three decades, there is an urgent call for innovative management strategies to prevent and reduce stone recurrence. This study aims to explore the evolving management needs in nephrolithiasis from both patient and healthcare provider perspectives. An expert-collaborative online survey comprising 10 targeted questions on kidney stone management was developed and disseminated. This survey was designed to gather comprehensive insights from patients, physicians and dietician and other person in the field of nephrolithiasis. Analysis of responses from 120 participants, including 45 nephrologists, 38 dieticians, 11 urologists, and 14 kidney stones patients followed in our hospital, revealed critical insights. A significant 97.5% emphasized the necessity of optimizing daily water intake, and 94.1% recognized the need for practical dietary modifications. Additionally, 88.3% of respondents found timely hydration reminders beneficial. Notably, monitoring urine color and pH was valued by 85% and 84.3% of the participants, respectively. A striking disparity emerged in the perception of fatigue and wellness monitoring, with 65% of patients prioritizing fatigue monitoring, a view less shared by healthcare professionals. Similarly, 71% of patients deemed wellness monitoring essential, highlighting a gap in understanding between patients and their caregivers. This study underscores the critical need for more tailored guidance on hydration strategies and the promise of remote urine parameters monitoring in nephrolithiasis management. The findings strongly advocate for a patient-centered approach, aligning medical recommendations with patient lifestyles and experiences, to enhance the effectiveness of nephrolithiasis management.

Keywords Kidney stones disease · Kidney stone management · Kidney stone prevention · Fluid intake · Urine monitoring

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Introduction

Kidney stone disease (KSD), is rapidly emerging as a significant public health concern, marked not only by its excruciating pain but also by complex systemic implications [1]. Traditionally perceived as an acute condition, KSD is now recognized as a chronic disorder of mineral metabolism [2]. This paradigm shift is pivotal, given the disease's rising prevalence and substantial impact on patients' quality of life [3, 4].

The epidemiology of KSD is exhibiting an alarming trend [5]. Over the past four decades, both the incidence and prevalence of kidney stones have escalated. This disease, once an incidental asymptomatic finding, is now often a painful recurrent disorder with considerable morbidity. The reported recurrence rate of KSD varies significantly, ranging from 6.1% to 66.9%, depending on various factors. These figures underscore the disease's chronic nature and the challenges in managing its recurrence.

Moreover, risk factors for symptomatic kidney stone recurrence include younger age, male gender, family history of stones, obesity, and pregnancy, among others [6].

In the United States, the economic burden of KSD has been staggering. From \$2.1 billion spent on stone disease in 2000, the projected expenditure is set to reach \$4.1 billion by 2030 [7, 8]. These figures represent only the direct costs, such as surgical therapy, which is the primary driver of these expenses. When considering indirect costs, including missed workdays, the economic impact becomes even more significant. For instance, the total indirect cost of stone disease in the United States, based on a privately insured population, was \$775 million, accounting for an average of 3.1 million missed workdays per year due to stone disease [9]. Despite considerable advances in the pathophysiological understanding and development of prevention guidelines, there remains a notable gap in managing this growing epidemic. Current prevention strategies, includes increased fluid intake, dietary modifications, and medication [10]. Regardless of significant improvements in KSD management, patient adherence to preventive pharmacological therapy is low (42% for alkali citrate and 52% for hydrochlorothiazide) [11]. Less than one-third (30.2%) of the 7980 adults with kidney stones who were prescribed therapy adhered to their regimen. It noted that adherence rates differed depending on the type of treatment prescribed: 42.5% for thiazides, 40.0% for allopurinol, and only 13.4% for citrate therapy [12]. The main reason for non-adherence in the alkali citrate group was the high number of pills required, while adverse drug effects were the primary concern in the hydrochlorothiazide group. Younger patients showed poorer adherence compared to older patients with chronic conditions and multiple medications [11].

Slightly more than half (51.1%) of the 8,950 patients who met the study eligibility criteria were adherent to preventive pharmacological therapy. The frequency of emergency room visits, hospitalizations and stone-related surgery was significantly lower in adherents than in non-adherents [13].

These findings highlight the issue of low adherence to medication regimens among patients with kidney stones and suggest the need for improved strategies to increase patient adherence. This highlights the urgent need for more effective strategies to enhance medication adherence among KSD patients. This gap between clinical recommendations and patient adherence contributes to the high recurrence rate of kidney stones, which can be as high as 50% within five years of an initial episode in adults and 3 years in children [14].

Recognizing these challenges, the International Society of Nephrology has called for a transformative change in managing kidney disease, focusing more on patient-centric education and addressing individual patient needs [15]. Current picture of the growing challenge of KSD

highlights the discrepancy between advancements in medical understanding and the real-world increase in disease prevalence and recurrence-motivated present work.

Our study aims to bridge this gap by obtaining information on the requirements to improve patient care, both by the patients themselves and healthcare providers, and to underlines the patient expectations in KSD management.

Methods

Study design

Our study employed a cross-sectional survey design to gather comprehensive data on the management of KSD. The aim was to capture a wide range of perspectives from both healthcare professionals and patients to understand the current practices and needs in KSD management.

Survey development

The survey was collaboratively developed with input from experts in kidney stone disease, including nephrologists and urologists. The questionnaire comprised 10 carefully crafted questions designed to cover various aspects of KSD management, such as dietary habits, fluid intake, medication adherence, and lifestyle changes. The survey was developed using Microsoft software, ensuring a standardized and user-friendly format.

Questions format

The questions were formulated to elicit responses based on the knowledge and experiences of the respondents. The multiple-choice questions were designed to gather specific information on practices and opinions. While the Likert scale questions gauged the level of agreement or importance participants attributed to various aspects of KSD management. We used the five-point scale ('essential', 'very useful', 'useful', 'neutral', and 'not useful'). This approach allowed us the quantification of subjective experiences, facilitating analysis and comparison of participants points of views on a topic.

Before distribution, the survey and its methodology were submitted to our local ethics committee and received approval from our board. We ensured the anonymization of the collected data to maintain participant confidentiality. The analysis was conducted with the primary purpose of enhancing the understanding of kidney stone management.

Participant recruitment and data collection

The survey targeted a predefined group of healthcare professionals—nephrologists, urologists, biologists, and dietitians—who were contacted via their professional networks through email. Additionally, patients were interviewed to ensure they comprehended the questions during their regular consultation process. This approach facilitated gathering diverse perspectives from both practitioners and patients. The survey was open for responses from February to May 2022, spanning three months to allow adequate participation.

Data analysis and presentation

All the responses recorded through the survey were analyzed using Microsoft software tools. The data were presented in a chart format, primarily using Excel software, for clear visualization and interpretation. Our analysis was primarily descriptive, focusing on frequencies and patterns in the responses.

Utilization of pareto chart

A key component of our data presentation was the Pareto chart. This bar chart, sorted by frequency, included a line graph to represent cumulative scores. It is a tool commonly used in quality control settings to identify critical factors in a process. In our study, the Pareto chart was instrumental in identifying key factors in the management of kidney stones, providing valuable insights into areas requiring attention or improvement.

Results

Survey participation and demographics

Through our survey and ancillary data collection methods, we received a total of 121 responses. After careful review, we identified and excluded one duplicate response from our dataset. Consequently, our final analysis was conducted with a robust sample of 120 participants. The professional distribution of the respondents was as follows: 45 nephrologists, 38 dietitians, 14 patients with kidney stones, 11 urologists, one biologist, and other specialties including one radiologist, one psychiatrist, two trade stakeholders, with the remaining being trainees in related fields (Fig. 1A). The Pareto chart, a bar graph sorted by frequency with a cumulative line graph, is instrumental in identifying critical factors in a process—in this case, the management of kidney stones. It illustrates the distribution of healthcare provider specialties and the proportion of patient participants, highlighting the importance of nephrologists and dietitians. The chart also depicts the distribution of participants across various institutional categories, excluding patients. It underscores the significant role of academic, private, and public institutions in kidney stone management.

Involvement in kidney stone management

Of the 86 professionals actively involved in kidney stone patient management, the majority (80.6%) see fewer than one patient per month. Approximately 6.3% see between 6

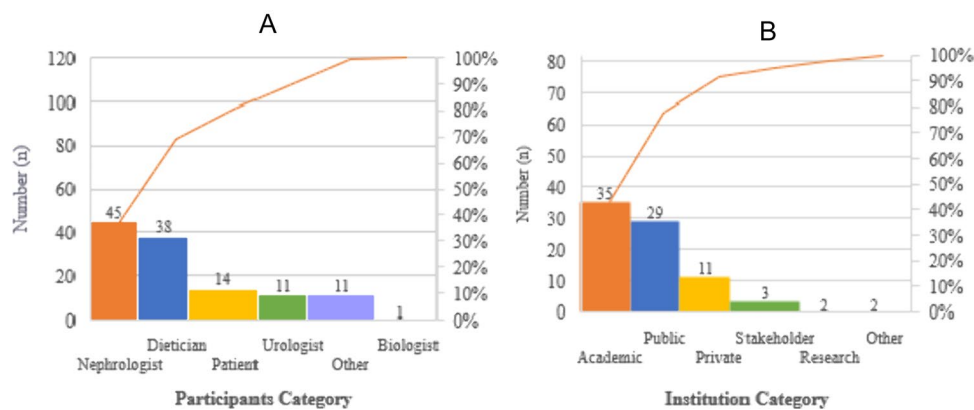


Fig. 1 Chart of Pareto containing the individual values represented in descending order by bars, and the cumulative total is represented by the line. The Pareto chart is a bar chart of frequencies sorted by frequency. The highest bars are on the left and includes a line showing the scores produced by adding the heights in order from left to right. This chart is used widely in quality control settings to identify critical factors leading to failure or defects in a process in this case management of kidney stones. (A) Representation of distribution regarding

health care providers specialties and proportion of patients participating in the survey, the line of Pareto indicates the importance of 3 critical participants categories involved in the management of kidney stones (nephrologists, dieticians, and patients). (B) Representation of participant’s distribution institution categories declared by the participants (excluding the patients). The line of Pareto indicates the importance of 3 critical institutions are involved in the management of kidney stones (academic, private, and public)

and 10 patients, 7.5% manage 11 to 25 patients, 10% handle 25 to 50 patients, and only three urologists reported managing more than 50 patients per month.

The primary reason cited by 60 participants for not being actively involved in kidney stone patient care was engagement in other types of medical activities. About 25% indicated a lack of experience in this area, and none of the respondents considered kidney stone disease management to be overly complicated or uninteresting.

Adaptation of water intake and patient adherence

A significant finding was the expressed need for adapting the daily volume of water intake for patients, which emerged as a primary consideration in patient care. This aspect, along with other specific questions related to improving kidney stone management and patient compliance, is elaborated in Fig. 2.

Key findings from the survey

Daily water intake

The recommendation to adjust the daily water intake was overwhelmingly supported, with 97.5% of participants (including 93 respondents considering it ‘essential,’ 20 ‘very useful,’ and 4 ‘useful’) acknowledging its significance. Only two respondents were neutral, and one found it unhelpful.

It indicates a universal consensus on the critical role of hydration in KSD management (Fig. 3).

Dietary advice

The importance of practical dietary advice was recognized by 94.1% of participants, with 83 considering it ‘essential,’ 26 ‘very useful,’ and 4 ‘useful.’ Neutral responses amounted to six, while only one participant found it unhelpful.

It is a high recognition of its importance, but the data might suggest a gap in practical application or patient adherence.

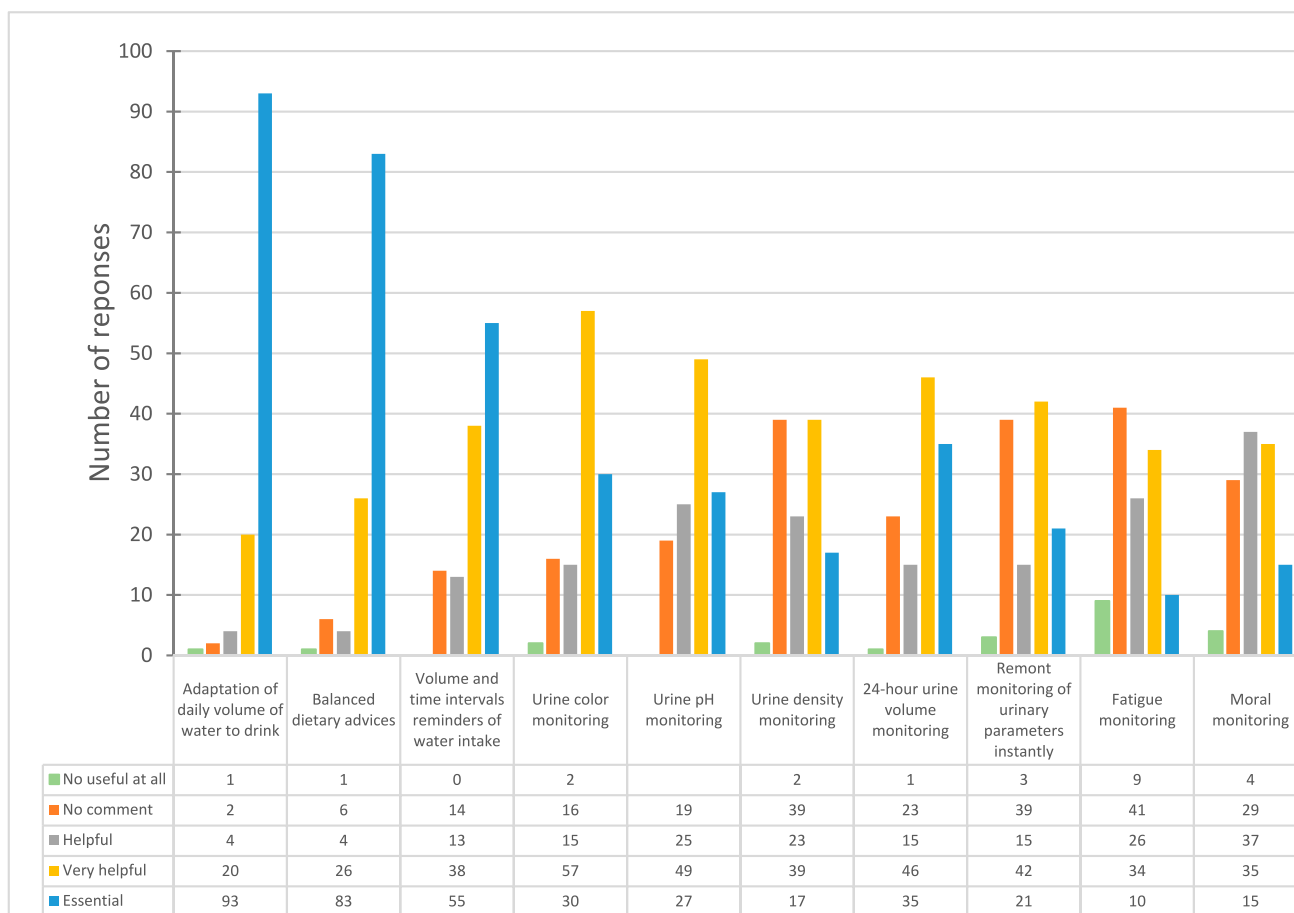


Fig. 2 Survey Insights on KSD Management Improvement: Illustrates survey responses on ten specific aspects for enhancing kidney stone management and patient adherence. Key areas include urinary parameter monitoring and patient well-being

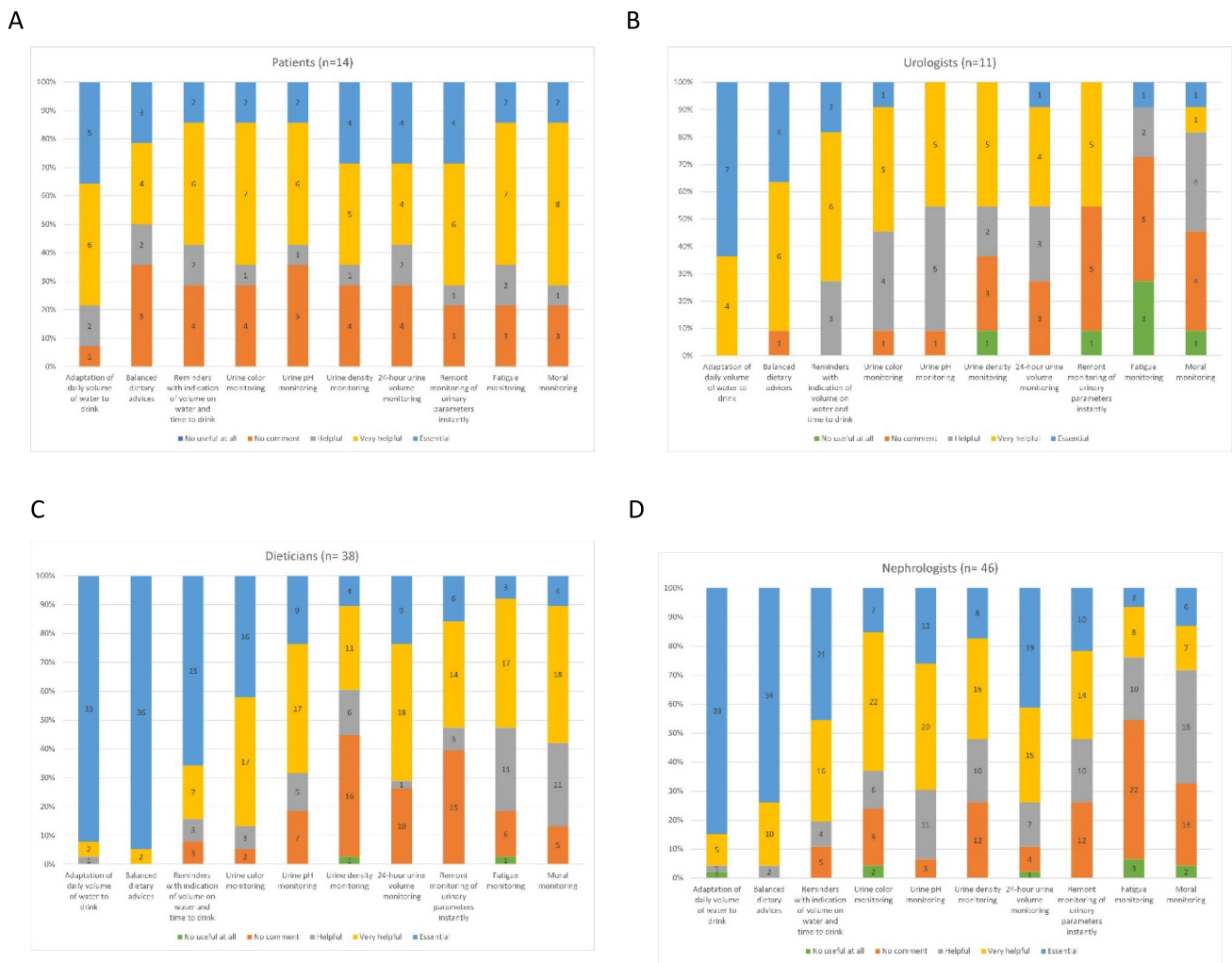


Fig. 3 Detailed Survey Breakdown by Respondent Category: Showcases survey results on ten critical management improvement areas, as perceived by patients (A), urologists (B), dietitians (C), and neph-

rologists (D). Focuses on the feedback regarding urinary parameters and patient feelings

Reminders for water intake

The idea of providing reminders, including the volume of water to drink and specific times for drinking, was regarded as valuable by 88.3% of participants (55 found it ‘essential,’ 38 ‘very useful,’ and 13 ‘useful’). Fourteen participants were neutral, and none found it unhelpful.

Strong support for reminders, indicates the potential effectiveness of digital tools or interventions in improving hydration habits.

Urine color monitoring

Monitoring urine color was considered ‘essential’ by 30 participants, ‘very helpful’ by 57, and ‘useful’ by 15, comprising 85% of the total responses. Only 16 were neutral, and 2 considered it not useful.

Majority view it as a crucial part of self-management, suggesting that patients value simple, visual methods to monitor their condition.

Urine pH monitoring

The utility of urine pH monitoring was acknowledged by 84.3% of respondents (27 found it ‘essential,’ 49 ‘very useful,’ and 25 ‘useful’). There were 19 neutral responses and no negative responses.

Widely acknowledged as valuable, these data reflect an awareness of the importance of biochemical monitoring in KSD.

Urine gravity monitoring

About 65.8% found monitoring urine gravity to be important, with 17 considering it ‘essential,’ 39 ‘very useful,’ and 23 ‘useful.’ Neutral and negative responses were 39 and 2, respectively.

Considered important, but with a notable number of neutral responses, suggesting a need for more education or clarity on its relevance.

24-h Urine volume monitoring

This parameter was deemed important by 79.1% of participants (35 considered it ‘essential,’ 46 ‘very useful,’ and 15 ‘useful’). Twenty-three were neutral, and only one found it unhelpful.

Recognized as important, highlighting the need for comprehensive monitoring in KSD management.

Remote monitoring of urinary parameters

The concept of remote monitoring for urine color, pH, density, and 24-h volume were viewed positively by 65% of participants. Neutral and negative views were held by 39 and 3 participants, respectively.

Positive views indicate an openness to technological solutions in managing KSD, though there is some hesitancy or lack of awareness about its potential.

Fatigue monitoring

Monitoring fatigue was seen as ‘essential’ or ‘very useful’ by 65% of patients, contrasting with the views of healthcare professionals (9% of urologists, 24% of nephrologists, and 52.6% of dietitians). Overall, 58.3% (10 ‘essential,’ 34 ‘very useful,’ and 26 ‘useful’) supported this, with 41 neutral and 9 negative responses.

Varied responses, with patients valuing this more than healthcare professionals. This discrepancy points to a need for a broader understanding of KSD’s systemic effects.

Mood monitoring

The majority (72.5%) considered mood monitoring ‘essential’ [15 participants], ‘very useful’ (35), or ‘useful’ (37). The response was ‘neutral’ for 29 and ‘not useful at all’ for 4. Again, a discrepancy was noted between patients (71% found it ‘very useful’ or ‘essential’) and healthcare professionals (18% of urologists, 28.8% of nephrologists, and 57.8% of dietitians).

Generally seen as important, particularly by patients, emphasizing the need to address the psychological aspects of KSD.

A significant finding was the divergence in perspectives between patients and healthcare professionals, particularly concerning fatigue and wellness monitoring. This highlights a gap in understanding patient experiences and the need for more patient-centric approaches in managing KSD.

Discussion

Our comprehensive survey paints a multifaceted landscape of KSD management, highlighting the diverse yet often discordant perspectives of healthcare professionals and patients. This narrative not only illustrates the complexities inherent in KSD care but also underscores the pressing need for a more integrated, patient-centered approach.

A mosaic of expert perspectives

Picture a scene where 45 nephrologists, 38 dietitians, 11 urologists, and a smattering of other specialists, including patients themselves, converge. Each brings a unique thread to the tapestry of KSD management. The result is a rich, multi-dimensional picture of the disease, but one that also highlights the need for a more cohesive, interdisciplinary approach.

In the clinician’s office

In this narrative, most healthcare professionals encounter kidney stone patients infrequently, with 80.6% seeing less than one patient per month. This rarity in their practice might contribute to an undercurrent of underestimation or even inadvertent neglect of KSD, hinting at a potential gap in routine healthcare. Delving deeper into the survey data reveals multifaceted and nuanced insights into KSD management, emphasizing the complexity of patient needs and the potential for improvements in care strategies.

Hydration management nuances

The near-universal recognition of the importance of water intake highlights a well-established medical consensus. However, the enthusiasm for reminders about water intake reveals an underlying challenge in patient behavior modification. This could suggest that despite understanding the importance of hydration, patients struggle with the practical implementation of these guidelines in their daily routines. The data might reflect a broader issue in chronic disease management—the gap between knowledge and consistent, long-term behavior change.

A study aimed at understanding kidney stone patients’ experiences with increasing fluid intake, a well-established preventive strategy, reported that adherence to this

recommendation is commonly below 50%. This indicates a significant gap in adherence to one of the most basic and cost-effective prevention strategies for kidney stones.

Dietary management challenges

The recognition of dietary advice's importance, contrasted with potential issues in adherence, points towards a disconnect between the provision of information and its practical application. This could be due to various factors, such as the complexity of dietary guidelines, socioeconomic barriers, or a lack of personalized dietary planning. However, 73.3% of patients adhered to the prescribed treatment (especially for hypocitraturia) and diet. The overall adherence rate was 61.2% for those treated with a single drug and 85.4% for those treated with multiple drugs. A significant increase in citrate levels was observed in patients with good adherence compared to non-adherent patients [16]. It suggests a need for more tailored dietary interventions, possibly involving more frequent and in-depth consultations with dietitians or the use of new technology to provide personalized dietary recommendations.

Comprehensive urine monitoring

The emphasis on urine monitoring reflects an awareness of its importance in tracking treatment efficacy, disease progression and management. The varied responses across different urine parameters might indicate differing levels of patient understanding or perceived ease of monitoring these aspects. For example, urine color is a simpler parameter to track compared to pH or gravity, which might require more specific tools or kits. Urine and stone analysis are crucial for diagnosis and treatment, with 24-h urine collection being the most useful method [17]. This suggests an opportunity for educational interventions or the development of user-friendly home monitoring kits.

Remote monitoring and digital health

Positive responses to remote monitoring align with global trends in telehealth and digital health adoption. This acceptance presents a significant opportunity for healthcare systems to invest in remote monitoring technologies, which could lead to more proactive and continuous management of KSD. However, the hesitancy or lack of awareness about its potential also suggests a need for patient education and demonstration of the efficacy of these tools. Despite the availability of numerous mobile applications for KSD, gaps in physician involvement, data security, and functionality persist. Effective advancement of mobile health tools for KSD requires oversight by urological associations and

patient groups, ensuring regular updates in content and data security [18].

Psychological aspects in KSD

The significant emphasis that patients place on fatigue and mood monitoring, compared to healthcare professionals, could indicate an under-addressed aspect of KSD management. This suggests that patients experience a considerable psychological and emotional burden, which might be overlooked in routine clinical practice. Addressing these aspects could involve incorporating mental health screenings and support into KSD management protocols.

Integrating patient perspectives

The divergent views between healthcare professionals and patients underscore a critical gap in understanding and addressing patient experiences and expectations in KSD management. This indicates a need for more empathetic, patient-informed approaches in clinical practice, potentially involving patient advisory boards or more regular patient feedback mechanisms in care planning. Indeed, study focused on patients' perception of kidney stone prevention within the emergency department found that 68% of patients did not receive any instructions about prevention. However, among those who did receive instructions, adherence was higher among educated patients (90%), those with insurance coverage (85%), and those with an income higher than \$1000 per month (76%). A significant majority, 71%, have faith in the effectiveness of stone prevention measures when provided. Additionally, a larger proportion, 82%, express interest in learning more about these preventive strategies. However, adherence to these measures is impeded by certain factors, with the primary reason being the cost, as indicated by 53.1% of the patients. This is followed by 18.8% of patients pointing out a lack of adequate explanation from emergency department physicians as another barrier. This data underscores the importance of patient education and cost-effective strategies in the management and prevention of kidney stones [19].

Future directions in KSD management

Our data points towards a more holistic, patient-centered approach in KSD management, integrating medical, lifestyle, and psychological aspects. This could involve multidisciplinary teams including nephrologists, dietitians, mental health professionals, kidney stone nurses, and patient educators, working collaboratively to address the multifaceted needs of KSD patients.

Indeed patient-reported outcomes were prominently used in analgesic control studies, but less so in other areas in a recent

systematic scoping review, covering literature from January 1, 2005, to March 30, 2021, aimed to evaluate the comparative effectiveness of various approaches in kidney stone disease [3]. There is a clear call for innovation in patient education and engagement strategies, possibly through digital platforms that provide interactive, personalized content and support.

Limitations

Our study acknowledges potential biases, including self-selection and non-response, limiting the generalizability of the findings.

Conclusion

In essence, the survey data not only highlights the current challenges in KSD management but also opens avenues for innovative approaches that holistically address patient needs, integrating medical, dietary, technological, and psychological aspects into a cohesive management plan.

By integrating patient-centered strategies with continuous education and leveraging technological advancements, we can significantly enhance adherence and mitigate the impact of KSD.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00240-024-01563-6>.

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Author contributions V.G. and A.P. designed and performed the study, analysed the data and wrote the main manuscript text. A.P. prepared figures. All authors reviewed the manuscript.

Data availability The data supporting the findings of this study are available upon request.

Declarations

Conflict of interests Dr. AP, has received a consultancy fee from Renal Care & Research. This professional relationship has been conducted separately and has not influenced the data collection, analysis, or findings of this study.

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