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Measuring quality of life among patients with urinary stone disease; A qualitative study



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ARTICLEINFO	A B S T R A C T
Article Type: Original	Introduction: Urinary stone disease is considered one of the common causes of emergency hospital admissions. Understanding the patients' perspectives on their quality of life is
Article History: Received: 8 July 2022	essential to evaluating the effectiveness of treatments and technologies. Objectives: This study aims to investigate the quality of life among patients with urinary stone disease.
Accepted: 1 September 2022 ePublished: 18 September 2022	Patients and Methods: A qualitative design was utilized. A purposeful sampling method was used to select the patients. Around 30 participants from patients were selected. The data were collected using semi-structured open-ended interviews with patients. Thematic analysis was
Keywords:	utilized to develop the themes.
Quality of life	Results: The main themes included pain, other physical symptoms, psychological symptoms,
Urinary stone disease	diet, Job-related activities, daily activities and lifestyle, and social and sexual life. The results
First stone former Ureteric stone	showed that pain, other physical symptoms, and changes in daily activities and lifestyle were the most reported negative life experiences. In contrast, job-related activities and psychological symptoms were the least reported negative life experience among patients with renal stone disease. The quality of life among patients with first stone former and ureteric stone was affected compared to patients with recurrent and/or renal stones. Conclusion: Our qualitative study provides deep insights into the impact of urinary stone
	disease on several aspects of quality of life. The findings are expected to aid in the development of patient-centered interventions for individuals suffering from urinary stone disease.

Implication for health policy/practice/research/medical education:

Pain, other physical symptoms, and changes in daily activities and lifestyle were the most reported negative life experiences. Job-related activities and psychological symptoms were the least reported negative life experience among patients with renal stone disease. The quality of life among patients with first stone former and ureteric stone was affected compared to patients with recurrent and/or renal stones.

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Introduction

The occurrence of urinary stone disease is high and has recently increased in developed and developing countries (1-3). The prevalence among general populations is estimated to be from 7% to 13% in North America, 5%– 9% in Europe, and 1%–5% in Asia mainly occurred among people aged between 35 and 55 years, while the risk of recurrence within five years of the first stone episode is estimated to be 50% (3). For this reason, the urinary stone disease has a significant burden on the health system and might lead to economic ramifications since most of the incidences have occurred among working and productive members of society (3,4).

Urinary stone disease is considered one of the common causes of emergency hospital admissions. Its clinical features ranged from minimal or asymptomatic disease to acute ureteric colic and systemic sepsis (4-8). The emergency treatment of urinary stone disease includes treating acute kidney injury, infection, and amelioration of pain (4). Once emergency treatment has been completed, an ongoing, complex, and multi-staged definitive treatment should be planned, especially for patients

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who suffer from multiple or recurrent stones. These treatments could be non-interventional or interventional. Non-interventional treatments may include expectant treatments, while interventional treatments may include shock wave lithotripsy, ureteroscopy, and percutaneous nephrolithotomy. However, their success rates are different according to conduct treatment options (7-11). For these reasons, urinary stone disease and its treatment(s) could negatively affect patients' quality of life (1,7).

Despite clear indications from the literature and guidelines, the need to incorporate patient-reported outcomes, patient treatment preferences, and resource efficiency are still suboptimal (original resource) (1-3). Most studies are focused on the limited aspects of clinical management (7,8,12).

Understanding the patients' perspectives on their quality of life is essential to evaluating the effectiveness of treatments and technologies. However, very few studies have been published to understand patient perspectives on patients' quality of life. Most of these studies were conducted in developed countries. They used a quantitative approach, knowing that the qualitative approach affords detailed information about patient views, which is an essential step in developing patientcentric measures (6-8).

Objectives

This study aims to investigate the quality of life among patients with urinary stone disease. The results are expected to offer detailed and baseline information about the urinary stone disease and treatment options that may play an important role in evaluating the treatment options and improving patient care based on patients' perspectives in developing countries (1).

Patients and Methods

Study design

A qualitative design was utilized. This design ensures a comprehensive evaluation from a broader perspective. This study was conducted with patients who visited five private urology clinics in Amman, Jordan.

Sample

A purposeful sampling method was used in the study to

select the patients. The number of required samples was determined by interviewing the eligible respondents until the data was saturation and no new data were obtained. Around 30 participants from patients have approached: 15 patients diagnosed with the urinary stone disease for the first time and 15 participants diagnosed with the urinary stone disease as recurrent stone former.

The eligible patients were adult patients 18 years upward, able to give informed consent, diagnosed with past or present urinary stone disease, complained of the disease symptoms within the last two weeks, spoke clearly, and gave written consent.

Data collection and procedure

The ethical approval to conduct the study was taken from the research office at Mutah university before completing the survey. The data were collected using semi-structured open-ended interviews with patients. The semi-structured open-ended interview protocol was developed based on a literature review (1,6-8). The protocol started with demographic questions: Age, gender, clinical feature: ureteric and renal stone, first time vs. recurrent stone formers, ureteric vs. renal stones, received treatment, and duration of disease that the researcher filled before asking the interview questions. The interview questions are listed in Table 1.

The researchers explained the purpose, significance of the study, and methods and confirmed voluntary participation during their visit. Participants were offered sufficient time to think about the study's participation and decide if they expressed their interest in taking part or learning more about the research. The respondents' initial acceptance was determined accordingly. If the initial approval was taken, the researchers asked the patients to sign the consent to conduct the interview. After taking permission from respondents who agreed to participate, trained interviewers performed the interview to conduct the qualitative study. The interviews were one-to-one in a private room without interruptions and in the Arabic language.

The interviews with patients were conducted within the first two weeks after the treatment. The interviews were recorded using a voice recorder. The recording usually started after the introduction of the participant, who was

Table	1.	Interview	questions
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Main Questions	Specific Questions		
Describe the symptoms of the urinary stone disease that you complained about?	 What are the physical symptoms of the urinary stone disease you complained about? How do these physical symptoms develop? What mental and emotional symptoms of the urinary stone disease that you complain about? 		
How do the urinary stone disease and its treatment affect your life?	 How do the urinary stone disease and its treatment affect your social life? How do the urinary stone disease and its treatment affect your work and carrier? How do the urinary stone disease and its treatment affect your activity of daily living? How do the urinary stone disease and its treatment affect your lifestyle and diet? 		

assigned a code number mentioned in the recording. The average time of the interview for patients was 28 minutes per person.

The study subjects were allowed to withdraw from the study if needed. The interviewers kept neutral and ensured a healthy relationship with the participants during and after the interviews. The authenticity of the data was maintained using different techniques such as active listening, unconditional acceptance, and clarification.

Statistical analysis

The recorded interviews were transcribed verbatim from the script. The Arabic data from interviews were translated into English by the research team. Finally, all data was controlled by a qualified translator and checked by study participants to attain the highest level of credibility. The transcribed and translated data was coded and analyzed accordingly. Transcribing, translating, and analyzing the data coincided with the data collection to influence interview guide refinement. Interview data were categorized and compared, and coded in the dataset. Thematic analysis for predefined themes (dimensions) was conducted and interpreted within the context of the existing literature. Many steps were c the process for thematic analysis:

- Reading and re-reading the interview transcripts was conducted to determine the themes.
- The sentences and phrases were unified and categorized.
- Category heading was selected for each group.

Table 2. Study themes

was 48 years (range 22–59). Six patients did not have any symptoms at the time of the interview. Fifteen patients were male (50%), and the same number were first-time stone formers (50%). Seventeen patients (56.7%) were diagnosed within the previous year. Fourteen patients were diagnosed with renal stones (46.7%). Around 52 themes were developed for quality of life. However, these themes were categorized into seven main themes. The main themes included pain, other physical symptoms, psychological symptoms, diet, Job-related activities, daily activities and lifestyle, and social and sexual life (Table 2).

Table 3 shows the most reported negative life experience among patients with urinary stone disease. The results showed that pain, other physical symptoms, and changes in daily activities and lifestyle were the most reported negative life experiences. In contrast, job-related activities and psychological symptoms were the least reported negative life experience among patients with renal stone disease.

Pain

As the results showed, around 96.7% (n=29) of patients reported the pain as a negative life experience after their diagnosis. From the total sample, most of the patients (60%) complained of a high score of pain that interrupted their life since the pain duration was more than three days among 86% of patients while the patients described their pain as intermediate pain (66%, n=20). Table 4 presents some examples.

All patients (100%) with first stone former and/ or ureteric stones reported the pain as a negative life experience. Moreover, the severity and duration of pain among these groups were more than the patients with

Theme	Description
Pain	 The score of pain (low, moderate, high) Continuous vs. intermittent pain Long-duration vs. short duration
Other Physical Symptoms	 Types of physical symptoms, severity and daily frequency Long-duration vs. short duration Including Nausea, vomiting, dysuria, hematuria, fever
Psychological Symptoms	 Aspects, severity and daily frequency Long-duration vs. short duration
Diet	 Aspects and severity Long-duration vs. short duration Including oral intake
Job-related activities	 Aspects and severity Long duration vs. short duration Including sick leave, annual leaves, effectiveness, performance
Daily Activities and lifestyle	 Aspects and severity Long duration vs. short duration Including sport, travel, hanging out activities, sleep disturbance, and non-comfortable sleep
Social and Sexual Life	 Aspects and severity Long duration vs. short duration Including visits, family interaction, mood, and sexual relationship

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Table 3. Major themes and frequency of reporting negative impacts on quality of life after disease diagnosis

		Stone formation		Place of stone	
Theme	Total (n=30)	First stone former (n=15)	Recurrence stone (n=15)	Ureteric stones (n=14)	Renal stones (n=16)
Pain	29 (96.7)	15 (100)	14 (93)	14 (100)	15 (93)
High score pain	18 (60)	11 (73)	7 (46)	12 (86)	6 (37)
Duration more than three days	26 (86)	13 (86)	13 (86)	14 (100)	12 (86)
Intermediate pain	20 (66)	13 (86)	7 (46)	14 (100)	6 (37)
Other physical symptoms	25 (83.3)	13 (86)	12 (80)	12 (86)	13 (81)
• Severity and frequency (M or H)	20 (66)	11 (73)	9 (60)	14 (100)	6 (37)
Duration more than three days	10 (33.3)	5 (33.3)	5 (33.3)	7 (50)	3 (19)
Psychological Symptoms	8 (26)	6 (40)	2 (13)	5 (36)	3 (19)
• Severity and frequency (M or H)	4 (13)	4 (27)	0 (0)	3 (21)	1 (6)
Duration more than three days	4 (13)	3 (10)	1 (7)	2 (14)	2 (13)
Diet	18 (60)	12 (80)	6 (40)	11 (79)	7 (44)
• Severity (M and/or H)	8 (24)	6 (40)	1 (7)	5 (36)	3 (19)
Duration more than three days	6 (20)	4 (27)	2 (13)	5 (36)	1 (6)
Job-related Activities	7 (23.3)	6 (40)	1 (7)	4 (29)	3 (19)
• Severity (M and/or H)	4 (13)	3 (10)	1 (7)	4 (29)	0 (0)
Duration more than three days	1 (3)	1 (7)	0 (0)	1 (7)	0 (0)
Daily activities and lifestyle	25 (83.3)	15 (100)	10 (67)	12 (86)	13 (81)
• Severity (M and/or H)	15 (50)	10 (67)	5 (33)	9 (64)	6 (38)
• Duration More than three days	9 (30)	6 (40)	3 (10)	5 (36)	4 (25)
Social and sexual life	15 (50)	10 (67)	5 (33)	10 (71)	5 (31)
• Severity (M and/or H)	8 (24)	6 (40)	2 (13)	7 (50)	1 (6)
• Duration more than three days	5 (17)	3 (10)	2 (13)	4 (29)	1 (6)

recurrent and/or renal stones since most patients with first stone former and/or ureteric stones reported pain with a high score (78% and 86%, respectively), long duration (86% and 100%, respectively), and as intermediate pain (86% and 100%%, respectively).

Physical Symptoms other than Pain

As the results showed, around 83.3% (n=25) of patients reported physical symptoms other than pain as a negative life experience after their diagnosis. Most of the patients (66%) complained of severe and frequent symptoms other than pain that interrupted their lives from the total sample. The most common symptoms were Nausea, dysuria, vomiting, fever, and hematuria, respectively. Only 33.3% (n=10) of patients reported that the duration of these symptoms was more than three days (Table 4).

Around 86% of patients with first stone former and/ or ureteric stones reported the physical symptom other than pain as a negative life experience. Moreover, these groups' severity among these symptoms was more than the patients with recurrent and renal stones. Most patients with first stone former and/or ureteric stones reported the symptoms as severe and frequent (73% and 100%, respectively). The duration of these symptoms was spent more than three days among patients with ureteric stones. There was no difference between the percentage of patients who reported a long duration of physical symptoms between patients with first renal former and patients with recurrent renal former (33.3% for each group).

Psychological symptoms

As the results showed, around 26% (n=8) of patients reported psychological symptoms as a negative life experience after their diagnosis. Approximately 13% of patients complained of severe, frequent, long-duration psychological symptoms that interrupted their lives from the total sample. The most common symptoms were fear, confusion, anxiety, and depression (Table 4).

Around 27% and 21% of patients with first stone former and/or ureteric stones, respectively, reported the psychological symptoms as a negative life experience. Moreover, the severity and duration of these symptoms among these groups were more than the patients with recurrent and/or renal stones since the patients with first stone former and/or ureteric stones reported the symptoms as severe and frequent and experienced for a long duration (27% and 21%, 10% and 14%, respectively).

Table 4. Major themes and quotes examples

Theme	Example quote
Pain	"The pain is uncontrolled. You cannot do anything during the pain attack that came suddenly almost every day." Patient 2 with recurrent renal stone
	"I do not experience pain like this. I was ready to remove all the organs to be relieved. It was repeated for one week." Week." Patient 5 with recurrent ureteric stones
Other physical symptoms	"I felt that my stomach like the laundry machine. I felt that I would vomit all the time. However, after two days, this symptom was significantly decreased." Patient 13 with first ureteric stone former
	"I felt that I should urinate, but I felt pain without any output when I went to WC." Patient 13 with first renal stone former
Psychological symptoms	"Palpitation suddenly happened even without physical symptoms. It may have resulted from the thinking about what is happening to me." Patient 8 with first ureteric stone former
	"After the pain attack, I don't prefer to stay beside my family. I fear to happen the attack again when I am alone." Patient 8 with first ureteric stone former
Changes in diet	"I know that drinking is essential for me, but I cannot do that." Patient 22 with recurrent renal stone
	"I do not eat for four days after I am diagnosed. I just drink some juice. My stomach was not good at all." Patient 19 with first ureteric stone former
Changes in job-related activities	"The focus on my tasks significantly decreased. The anxiety negatively affected my performance." Patient 15 with recurrent ureteric stone former
	"I did not go to work for two days. I feared becoming in pain during my work." Patient 1 with recurrent renal stone
Changes in daily activities	"I cannot sleep very well. I wake up every 30 minutes for two days." Patient 17 with first former renal stone
	"I canceled all social activities. I do not need anyone to see me in pain." Patient 20 with first ureteric stone former
Changes in social and sexual life	"I felt that I could not interact very well with others because no one understands what I feel." Patient 18 with recurrent ureteric stone former
	"no desire to be in physical contact with anyone. I lost my mood during this period." Patient 16 with recurrent renal stone

Changes in diet

As the results showed, around 60% (n=18) of patients reported changing their diets as a negative life experience. From the total sample, about 24% of patients complained of significant changes in their diet that interrupted their lives. The most common symptoms were decreased oral intake and loss of appetite, respectively. The duration of this was reported as more than three days among 20% of patients (Table 4).

Around 40% and 36% of patients with first stone former and/or ureteric stones respectively reported an adverse change in their diets. Moreover, the severity and duration of these symptoms among these groups were more than the patients with recurrent and/or renal stones since the patients with first stone former and/or ureteric stones reported these changes as severe and experienced for a long duration (40% and 36%, 27% and 36%, respectively).

Changes in job-related activities

As the results showed, around 23.3% (n=7) of patients

reported changes in job-related activities as a negative life experience. About 13% of patients complained of significant changes in their job-related activities that interrupted their lives from the total sample. The most common changes were decreased effectiveness, work performance, high sick leaves, and leaves. The duration of this was reported as more than three days among only one patient (Table 4).

Around 40% and 29% of patients with first stone former and/or ureteric stones respectively reported an adverse change in their job-related activities. Moreover, the severity and duration of these symptoms among these groups were relatively more than the patients with recurrent and/or renal stones since the patients with first stone former and/ or ureteric stones reported these changes as severe and experienced for a long duration (10% and 29%: 7% and 7%, respectively).

Changes in daily activities and lifestyle

As the results showed, around 83.3% (n=25) of patients

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reported daily activities and lifestyle changes as a negative life experience. Approximately 50% of patients complained of significant changes in daily activities and lifestyles that interrupted their lives from the total sample. The most common changes were sleep disturbance, decreased travel, hanging out activities, lack of sport, and non-comfortable sleep. The duration of this was reported as more than three days among 30% of patients (Table 4).

Around 100% and 86% of patients with first stone former and/or ureteric stones respectively reported an adverse change in their daily activities and lifestyle. Moreover, the severity and duration of these symptoms among these groups were relatively more than the patients with recurrent and/or renal stones since the patients with first stone former and/or ureteric stones reported these changes as severe and experienced for a long duration (67% and 64%: 40% and 36%, respectively).

Changes in social and sexual life

As the results showed, around 50% (n=15) of patients reported social and sexual life changes as a negative life experience. About 24% of patients complained of significant changes in daily activities and lifestyles that interrupted their lives from the total sample. The most common changes were decreased interaction, social visits, and loss of sexual desire, respectively. The duration of this was reported as more than three days among 30% of patients (Table 4).

Around 67% and 71% of patients with first stone former and/or ureteric stones, respectively, reported an adverse change in their social and sexual life. Moreover, the severity and duration of these symptoms among these groups were relatively more than the patients with recurrent and/or renal stones since the patients with first stone former and/or ureteric stones reported these changes as severe and experienced for a long duration (40% and 50%: 19% and 29%, respectively).

Discussion

This study looked into the quality of life in patients with urinary stone illness, the differences between renal stone and ureteric stone, and the difference between first stone formation and recurring stone. The findings provided thorough information regarding the urinary stone illness to evaluate treatment choices and improve patient care from the patients' perspective. Seven main themes were initiated: pain, other physical symptoms, psychological symptoms, diet, Job-related activities, daily activities and lifestyle, and social and sexual life. These themes are also mentioned in many previous studies. This indicated that our results were consistent with another study that discussed the quality of life among patients with urinary stone disease (1,7).

According to the findings, pain and other physical symptoms were the most reported lousy life experiences. This result demonstrated the importance of adequate physical symptom management in improving the quality of life among patients with urinary stone disease and ureteric stone, as approximately 96.7 percent (n=29) and 83.3% (n=25) of patients reported pain and physical symptoms other than pain as a negative life experience following their diagnosis, respectively. This result was consistent with other previous studies (1,7).

The majority of patients complained of severe pain that disrupted their lives since it lasted for more than three days in the majority of cases. This finding may explain the disease's severe influence on daily activities, lifestyle, as well as other life aspects like as social and sexual life, particularly among patients with the first stone formation and/or ureteric stones who experienced pain and other physical symptoms with a high score and frequent, and for a long time. These symptoms may consider the origin of other problems related to the quality of life, such as social and sexual life and diet. This result was consistent with other previous studies. Regular follow-up is needed for patients with renal stone disease, especially those with the first stone formation and/or ureteric stones (1,6,7).

Approximately 27% and 21% of patients with the first stone formation and/or ureteric stones, respectively, experienced psychological symptoms as a bad life experience, particularly dread, perplexity, anxiety, and despair. Furthermore, the severity and length of these symptoms were more significant in these groups than in patients with recurring and/or renal stones because patients with the first stone formation and/or ureteric stones rated the symptoms as severe, frequent, and lasting a long time. Although a small percentage of people reported this topic, psychological problems can significantly impact the human outcome because they affect all elements of life (13,14). A well-structured assessment and intervention are required for those patients to enhance and follow the patients' psychological health as indicated by many previous studies (1,7,14).

Approximately 60% (n=18) of patients reported changing their diets due to a poor life experience. However, these symptoms' severity and extended duration were not reported in high numbers. It may be due to practical and early management of other symptoms, especially physical signs that indicate these changes. Proper and effective nutritional status and follow up are required to enhance the quality of life, especially among patients with first stone former and/or ureteric stones who reported these symptoms more than other subgroups (15-17).

According to the findings, approximately 23.3 percent (n=7) of patients reported changes in job-related activities as an inadequate life experience. Thirteen percent of patients said significant changes in their job-related activities decreased effectiveness and work performance and led to high sick leaves and leaves. However, the duration and frequency of these changes were very low. Early diagnosis and management may be essential to decrease the incidence of these impacts, especially among

the patients with first stone former and/or ureteric stones who reported these symptoms more than other subgroups (1,7).

According to the findings, the most common alterations in daily activities and lifestyle, particularly among patients with the first stone formation and/or ureteric stones, were sleep disturbance, decreased travel, hanging out activities, sport, and non-comfortable sleep. These symptoms could be the result of discomfort or physical problems. To lessen the impact, education about relaxing techniques and effective and early management are recommended. The most common symptoms in the sexual and social life theme are a decrease in sexual contact, social visits, and loss of sexual desire, particularly among patients with the first stone formation and/or ureteric stones (1,7,17).

Conclusion

This study aims to measure the quality of life among patients with the urinary stone disease and its subgroups. Seven main themes were developed: pain, other physical symptoms, psychological symptoms, diet, Job-related activities, daily activities and lifestyle, and social and sexual life. The most reported symptoms were related to pain and other physical symptoms. The results showed that the quality of life among patients with first stone former and ureteric stone was affected compared to patients with recurrent and/or renal stones.

Limitations of the study

Finally, our study has many limitations; the limited qualitative studies discussed the quality of life among patients with renal stone disease, and its subgroups are considered the main limitation. The other limitation includes the low sample size since the study was done in private clinics where the patients did not easily accept to participate due to time constraints. Finally, some symptoms, especially those related to sexual life, may not be well explained by the patients due to cultural issues.

Authors' contribution

Conceptualization: Malik Ayyad. Data curation: Omar Ayaad. Formal analysis: Omar Ayaad. Investigation: Malik Ayyad. Methodology: Malik Ayyad and Omar Ayaad. Project administration: Malik Ayyad. Resources: Malik Ayyad. Supervision: Malik Ayyad. Validation: Malik Ayyad. Writing-original draft: Malik Ayyad and Omar Ayaad. Writing-review & editing: Malik Ayyad and Omar

Conflicts of interest

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The authors declare that they have no competing interests.

Ethical issues

The research followed the tenets of the Declaration of Helsinki. The Ethics Committee of Mutah University of Medical Sciences approved this study (0048/2021). Accordingly, written informed consent was taken from all participants before data collection. This study was not extracted from M.D, Ph.D., or MSc thesis.

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