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Exploring Patients' Experiences of Self-Management After Percutaneous Nephrolithotomy: A Qualitative Study

Jing Ji[1], Changying He[2], Jianing Cao[1], Ning Cao[1], Xiaohuan Peng[1], Lifang Huang[2,*]

[1]Youjiang Medical University for Nationalities, Baise, Guangxi, China
[2]Affiliated Hospital of Youjiang Medical University for Nationalities, Baise, Guangxi, China
Correspondence Author

Abstract: ***Objective**: To explore the experiences and needs related to self-management behaviors among patients following percutaneous nephrolithotomy, based on the Integrated Theory of Health Behavior Change. **Methods**: A descriptive qualitative study was conducted. Fifteen patients treated in the urology department of a tertiary hospital in Baise City, Guangxi, China, from September to December 2024 underwent semi-structured interviews. Data analysis was performed using Nvivo 12.0 software. **Results**: Three themes and nine subthemes were identified: insufficient knowledge and beliefs (lack of disease knowledge, cognitive biases, negative health beliefs); poor self-regulation abilities (insufficient symptom management skills, poor health behavior adherence, external environmental influences); and a desire for social support (including the need for family support, expectations for professional and individualized guidance from healthcare providers, and mutual influence among peers). **Conclusion**: Knowledge and beliefs, self-regulation skills and capabilities, and social support are interconnected factors influencing patients' implementation of effective self-management behaviors. Meeting patients' informational needs and social support requirements while fostering supportive environments can promote sustained healthy behaviors.*

Keywords: Percutaneous Nephrolithotomy, Integrated Theory of Health Behavior Change, Self-management behavior, Qualitative study, Nursing.

1. Introduction

The prevalence of urinary tract stones in China is approximately 6.5%, with a higher incidence observed in males than in females [1], The recurrence rate within five years after treatment is approximately 30% [2]. Percutaneous Nephrolithotomy (PCNL) is gradually replacing traditional open surgery for treating complex kidney stones. Although it demonstrates excellent efficacy in stone clearance, postoperative complications remain a challenge in clinical practice, with approximately 15% of patients experiencing complications postoperatively [3]. Research indicates that postoperative complications in patients are closely associated with their self-management behaviors. Due to insufficient knowledge about kidney stones and weak self-management capabilities, patients experience negative impacts on postoperative recovery [4]. Research indicates that self-management behaviors among patients following PCNL are suboptimal. Therefore, this study recruited discharged PCNL patients to examine their experiences and perceptions of self-management, with the goal of identifying the challenges and needs they face in managing their care [5]. Ryan (2009) [6] proposed the Integrated Theory of Health Behavior Change (ITHBC), a patient-centered and dynamic mid-range theoretical framework. The theory primarily encompasses three domains: knowledge and beliefs, self-regulation skills and abilities, and social facilitation. It has demonstrated significant effectiveness in elucidating the process of patient behavior change. Cheng L et al. [7] identified factors influencing medication safety in home-based chronic heart failure patients based on the ITHBC theory, providing a basis for ensuring medication safety. Guided by the ITHBC framework, this study used a descriptive qualitative approach to explore the experiences and needs associated with self-management among PCNL patients. The findings aim to inform the development of tailored self-management interventions, improving their relevance and effectiveness in supporting patients' self-care.

2. Objects and Methods

2.1 Research Subjects

Purposive sampling was used to recruit discharged PCNL patients who were treated in the Department of Urology at our hospital between September and December 2024. The principle of maximum variation was applied during the selection process to ensure diverse representation. The sample size was determined by data saturation, defined as the point at which no new themes emerged.

Inclusion Criteria: (1) Age ≥18 years old; (2) PCNL with a double-J stent left in place postoperatively; (3) Possesses a certain level of comprehension and verbal expression skills; (4) The patient has provided informed consent and voluntarily participates in this study.

Exclusion Criteria: (1) Combined severe heart, brain, and kidney diseases; (2) Suffering from psychological or mental issues.

2.2 Research Methods

2.2.1 Establish the Interview Outline

A research team was established to develop the initial interview guide. This process involved literature review and synthesis, group discussions, and use of the ITHBC framework. The draft guide was then refined based on pilot interviews with two participants, resulting in the final interview guide. (1) How did you discover you had kidney stones? (2) How much do you know about kidney stones? (3)

How do you manage your fluid intake and physical activity? How do you monitor changes in your weight, urine output, and other related indicators? How do you respond when you experience symptoms such as painful urination, blood in the urine, or lower back pain? (4) Do you think these behaviors, such as increasing water intake or modifying your diet, can help prevent the recurrence of kidney stones? Why or why not? (5) When you encounter difficulties or are unable to maintain these health behaviors (such as diet, fluid intake, or physical activity), how do you usually cope? (6) During your illness, how have your family, friends, or colleagues supported you in managing your kidney stones on a daily basis? What additional support would you like to receive? (7) Do you have any expectations or suggestions?

2.2.2 Data Collection and Quality Control

Researchers who have undergone systematic training in qualitative research and mastered research methodologies and interview techniques will conduct one-on-one interviews with participants. Interviews will take place one month after discharge when patients return to the hospital for double-J stent removal. Prior to the interview, the purpose of the interview will be explained to the research subjects, and confidentiality principles will be assured. Interview materials include a general information questionnaire, informed consent form, and interview record form. Interviews were conducted in quiet, private rooms, with each session lasting 20-40 minutes. Prior to recording, informed consent was obtained from participants. With consent secured, interviews were fully audio-recorded. Researchers attentively listened while documenting participants' facial expressions, gestures, and emotional shifts. Leading questions were avoided. Clarification was sought for ambiguous statements, and interview outlines were flexibly adjusted based on actual circumstances. To protect participant privacy, all interview content was anonymized, with participant names replaced by number.

2.2.3 Data Organization and Analysis

Following the interviews, two researchers transcribed the audio recordings into text within 24 hours. Data were analyzed using directed content analysis, with the ITHBC framework serving as the classification outline. Repeatedly listened to recordings and read transcripts, analyzing each sentence to extract semantic units. Utilized Nvivo 12.0 software for coding, applying the ITHBC framework to categorize themes under Knowledge and Beliefs, Self-Regulatory Skills and Abilities, and Social Support. Meticulously reviewed transcripts sentence by sentence, grouping similar codes under corresponding themes, and further analyzed to develop themes and sub-themes.

3. Results

3.1 General Information of Participants

This study included a total of 15 patients. General Information of Participants are presented in Table 1.

Table 1: General Information of Participants

Number	Age	Gender	Educational background	Occupation	Monthly household income (RMB)	Intraoperative blood loss (ml)
P1	51	Male	Junior High School	Farmer	3000-5000	10
P2	54	Male	vocational high school	Technical Professionals	>5000	20
P3	58	Female	High School	Self-employed	>5000	10
P4	55	Female	Elementary School	Farmer	<3000	30
P5	58	Female	High School	Others	3000-5000	50
P6	44	Female	vocational high school	Others	>5000	20
P7	62	Male	High School	Farmer	<3000	100
P8	61	Female	Junior High School	Unemployed	3000-5000	5
P9	37	Male	vocational high school	Staff member	>5000	10
P10	58	Male	Junior High School	Farmer	<3000	30
P11	40	Male	Junior High School	Manual worker	3000-5000	50
P12	34	Male	High School	Manual worker	>5000	70
P13	32	Female	High School	Others	3000-5000	10
P14	54	Male	Undergraduate	Teacher	>5000	30
P15	71	Male	Junior High School	Farmer	<3000	100

3.2 Topic 1: Lack of Knowledge and Beliefs

3.2.1 Lack of disease knowledge

Many participants expressed a strong need for health-related knowledge, particularly regarding dietary management and recurrence prevention, and reported relying heavily on education and guidance provided by healthcare professionals. However, some patients—especially those with lower educational attainment or limited habits of recording health information—tended to forget this information after discharge, which adversely affected the sustainability of health behaviors and the consistency of self-management practices. P10: "I just want to know clearly what I should eat and what I should avoid in terms of diet." P7: "Please help me make an image showing what I can eat and what I should avoid—a complete version—so that I won't easily forget it after I'm discharged." P6: "Tell me more about kidney stone recurrence. I'm really worried because I had them once before, and now it has happened again."

3.2.2 Cognitive bias

The interviews revealed that most participants, due to insufficient knowledge about the disease, held misconceptions regarding the etiology, progression, and recurrence of kidney stones. As a result, they were unable to accurately assess the appropriateness of their own behaviors and often relied on subjective judgment when making health-related decisions. P2: "At home, I usually don't drink much water. I only drink when I feel thirsty and don't drink otherwise, and my meals are irregular." P8: "I am not sure

whether tofu can lead to recurrence, and as a result, I am now afraid to eat it." P15: "In just six months, stones couldn't have formed so quickly; it's possible they weren't completely removed before."

3.2.3 Negative health beliefs

The patient exhibits distorted health beliefs, perceiving stone recurrence as inevitable. These negative health beliefs undermine adherence to dietary and hydration practices, impeding the development of effective self-management habits and hindering disease prevention and recovery. P3: "I had kidney stones removed two years ago, but they've come back again. Kidney stones are a constitutional issue — drinking water doesn't help." P4: "When I first discovered the kidney stone, the doctor said it was very small. I controlled my diet and ate lighter meals, but look—it's still grown larger. Dietary control is completely useless." P11: "I usually have social obligations and go out drinking every day. If I don't drink, I feel like I won't have any friends."

3.3 Topic 2: Poor Self-regulation Skills

3.3.1 Insufficient symptom management skills

Some patients are unaware of how to manage complications after they occur. P3: "I did not take my lower back pain seriously at first and chose not to seek treatment. When the pain became unbearable, I had no choice but to return to the hospital." P10: "Within one or two days after returning home from my last hospitalization, I experienced painful urination with visible blood. I initially thought it would resolve on its own, but the symptoms did not improve and persisted until this hospital visit." P12: "With the double-J stent in place, I experience severe pain during urination. I do not know how to relieve the discomfort and am unsure whether it is appropriate to take pain medication." P14: "Following my previous discharge, I frequently experienced urinary urgency and frequency, but I was uncertain whether reducing my fluid intake was appropriate."

3.3.2 Poor adherence to health behaviors

Despite having some degree of disease awareness and experiential knowledge, certain patients find it difficult to maintain long-term adherence to healthy behaviors. P11: "Although I am aware that excessive consumption of soy products is not advisable, I still prefer them and consume them regularly." P9: "Although I intend to increase my daily water intake, I am unable to do so and can manage no more than approximately one liter per day." P12: "I usually prefer drinking beverages. I know they are not good for me, but I still like them. I find plain water tasteless and difficult to drink."

3.3.3 External environmental factors

A range of objective environmental factors exert varying levels of influence on patients' ability to implement self-management behaviors. P1: "I work in agriculture, so it is not feasible for me to stay at home and drink large amounts of water every day." P7: "After a long day of work, I am too exhausted to have any energy for exercise." P6: "I don't have time to exercise every day because of work. I only occasionally jump rope, which I consider as a form of weight control." P8: "Since I started coming here to take care of my grandchildren, I have been falling ill more often and have reduced my physical activity. When I used to work at home, I did not have such problems." P2: "I am usually very busy at work and do not have time to drink water."

3.4 Topic 3: Desire for Social Support

3.4.1 Desire for family support

Some patients lack active support from family members during their recovery process. Due to reasons such as busy work schedules or insufficient understanding of the illness, family members fail to provide the necessary guidance and supervision. P8: "I would like my child to come and keep me company, but they are very busy with work. My child works at a bank and has no time to bring me meals, as they also have to take care of their own children and cannot look after me." P15: "Sigh… I kept telling my child about my illness, but they became annoyed, saying it had been treated many times without improvement and asking what I could do. So I decided to come here myself, registered at the hospital, and got some medicine from the traditional Chinese medicine department to take at home." P10: "After learning I had kidney stones, I initially did not inform my child to avoid troubling them. It was only after the doctor advised against delaying treatment that I contacted my son and asked him to take me to the hospital for surgery." P13: "My husband often reminds me to drink water at home, and we often engage in walking and other physical activities together."

3.4.2 The need for professional and personalized guidance for healthcare personnel

Due to the overwhelming amount of online health information and the difficulty in distinguishing fact from fiction, patients struggle to obtain accurate health guidance. They also hope to continue receiving remote guidance and support from healthcare professionals after discharge to promptly address questions and ensure standardized health behaviors. P5: "The doctor mentioned diet and complications, but I forgot all that pretty quickly. I'm not sure if the stuff I found online is reliable either." P9: "After my last hospital discharge, I had red urine for several consecutive days. I stayed in bed for days, but it didn't improve. I didn't know what to do." P2: "After being discharged from the hospital last time, I suddenly experienced severe lower back pain at home, along with blood in my urine. I'm not sure if this is normal, and I'm feeling extremely anxious."

3.4.3 Peer influence among patients

Patients share their experiences and feelings with one another, but sometimes they also exchange folk remedies and misguided dietary advice, leading patients to make unscientific health decisions. P13: "I came across an online recommendation for a folk remedy that claimed to offer a complete cure, and I nearly believed it." P12: "They told me to take this Chinese herbal medicine, but it depends on individual constitution. The medicine worked for them and helped pass the stones, but it did not work for me, as I couldn't pass them, even though they had already passed theirs." P5:

"A friend told me how he passed his kidney stones, and when I followed his method, it really worked."

4. Discussion

4.1 Enhance Patient Knowledge and Beliefs

Knowledge is the foundation for individual behavioral change, while belief serves as the internal driving force [8]. Mastering disease knowledge and securing access to healthcare information are prerequisites for successfully advancing patient self-management [9]. The findings of this study indicate that most patients are unable to accurately execute health behaviors due to limitations in disease cognition or rigid behavioral patterns. Examples include uncontrolled eating habits, neglecting adequate hydration, and being unaware of how to manage complications when they arise. This poses challenges in transforming patients' self-management behavior cognition and improving medication adherence. This finding is consistent with the results of Emma's study [10]. Patients' desire for health information [11]: When patients fail to access scientific and systematic health information, they often lack awareness of the risk factors for stone formation and struggle to recognize the importance of daily health behaviors in disease management. Most patients demonstrate weaknesses in disease management and coping strategies. Although healthcare providers routinely deliver educational materials during clinical practice, the content tends to be fragmented, lacking a comprehensive framework and consistent reinforcement. This makes it difficult to support patients in making effective decisions during their home-based care phase. Evidence from prior research indicates that employing a variety of health education approaches, including video, visual and textual materials, audio instruction, and immersive interactive experiences [12], can increase patient engagement and understanding, ultimately promoting better self-management skills. Furthermore, utilizing digital platforms, including WeChat and 'Internet Plus', to provide continuous nursing care allows patients to obtain health information and behavioral guidance at their convenience, facilitating the consistency and long-term adherence to healthy behaviors.

Shortly after being diagnosed with kidney stones, patients altered their dietary habits; however, their motivation tended to wane over time as they continued living with the disease [11]. Consequently, the persistence of self-management behaviors gradually declined, and patients generally held low beliefs regarding the impact of their own behaviors on disease recovery and recurrence [13]. Healthcare professionals need to continuously emphasize patients' agency in disease prevention and management, assess the sources of patients' motivation, appropriately use case-based approaches, highlight the benefits of behavior change, and support the maintenance of intrinsic motivation.

4.2 Enhance Patients' Self-regulation Skills and Abilities

The findings of this study indicate that most patients lack adequate symptom management skills, exhibit insufficient awareness of self-monitoring, and struggle to accurately identify and assess symptom management approaches. This finding is consistent with Chen [5]. After surgery, patients typically need to have a double-J stent in place for about one month. During this period, they are prone to a range of symptoms, including lower back and abdominal discomfort, urinary tract infections, hematuria, urinary frequency, and dysuria [14, 15]. These complications significantly increase the complexity and difficulty of symptom management at home, placing higher demands on patients' ability to recognize and manage their symptoms. Therefore, healthcare providers should place emphasis on cultivating patients' self-regulation abilities. Self-regulation is the process used to modify health behaviors. It is a critical skill necessary for effectively integrating health behavior changes into daily routines and lifestyles [6]. Through this process, patients can proactively apply corresponding strategies to maintain and consolidate healthy behaviors. Patients' lack of disease management experience or discrepancies between actual symptoms and expectations can impair their self-regulation and assessment abilities [16]. Therefore, we should encourage patients to participate in healthcare decision-making, assist them in setting phased goals and plans, guide them to reflect on past disease management experiences, evaluate the effectiveness of self-management at each stage, and enhance their sense of involvement and accomplishment.

4.3 Emphasize the Importance of Supporting Diverse Needs

The findings of this study indicate that patients require multiple forms of social support following PCNL. Changes in patient behavior are significantly influenced by external support from healthcare providers, family, and peers [11]. Patients' self-management motivation tends to decline after discharge, emphasizing the crucial role of healthcare providers in continuously reinforcing patient autonomy in managing kidney stones. The emotional and practical support offered by family members represents an essential external resource. This highlights the significant influence of social contextual factors on patients' disease comprehension, decision-making participation, and the formation of sustained self-management behaviors [10], offering valuable insights for designing future intervention strategies. Family members, especially spouses, can remind patients to adhere to dietary recommendations, assist in preparing healthy meals, and share relevant health information. Through these interactions, they develop a shared understanding of the disease, which can positively influence patients' coping behaviors [17]. For patients, the support and guidance provided by healthcare professionals can significantly enhance their ability to implement healthy behaviors and strengthen their confidence in managing their health. Most participants are eager to exchange experiences with others. Through sharing experiences, emotional resonance, and behavioral encouragement among fellow patients, self-efficacy and self-management capabilities can be effectively enhanced. We can organize regular patient peer-support meetings, allowing individuals to share effective experiences and coping strategies accumulated during self-management. This approach can further enhance patients' confidence and motivation in managing their condition.

5. Summary

This study conducted in-depth interviews with 15 patients who underwent PCNL using the ITHBC framework. It analyzed barriers and needs in patients' self-management processes, primarily including: lack of disease knowledge, cognitive biases, negative health beliefs, inadequate symptom management skills, poor adherence to health behaviors, external environmental influences, and the need for multidimensional social support. In designing future PCNL self-management programs, these factors should be carefully considered to meet patients' needs for information and social support, thereby facilitating the sustained adoption of healthy behaviors over the long term. However, this study has certain limitations, such as the inclusion of patients with relatively low educational attainment and from a single source. Future research should explore multi-center studies involving patients across multiple age groups and with higher educational levels to achieve a more comprehensive assessment.

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Author Profile

Lifang Huang corresponding author, Female, Affiliated Hospital of Youjiang Medical University for Nationalities, Baise, Guangxi, China; E-mail: Baiself@163.com

Jing Ji First author, Female, Youjiang Medical University for Nationalities, Baise, Guangxi, China; E-mail: 1336256127@qq.com

Changying He Female, Affiliated Hospital of Youjiang Medical University for Nationalities, Baise, Guangxi, China; E-mail: 764699113@qq.com

Jianing Cao Female, Youjiang Medical University for Nationalities, Baise, Guangxi, China; E-mail: 1764753354@qq.com

Ning Cao Female, Youjiang Medical University for Nationalities, Baise, Guangxi, Chin; E-mail: 2834730861@qq.com.

Xiaohuan Peng Male, Youjiang Medical University for Nationalities, Baise, Guangxi, China; E-mail: 1316889381@qq.com