


Exploring the Hidden Struggles: A Qualitative Insight into Urinary Incontinence Among Prostate Cancer Survivors Post-Surgery

Na Sun ^{1,2}, Yanhong Gu^{1,2}

¹Department of Nursing, Shanghai Fifth People's Hospital, Fudan University, Shanghai, People's Republic of China; ²School of Nursing, Fudan University, Shanghai, People's Republic of China

Correspondence: Yanhong Gu, Director of Nursing Department, Shanghai Fifth People's Hospital, Fudan University, 801 Heqing Road, Minhang District, Shanghai, 200240, People's Republic of China, Tel +86-18516261081, Email reddy_gu@163.com

Objective: This study aimed to explore the experiences and challenges of prostate cancer patients suffering from urinary incontinence following radical prostatectomy.

Methods: A descriptive qualitative research design was employed. Purposeful sampling was used to select 22 prostate cancer patients who underwent radical prostatectomy and experienced urinary incontinence after surgery. These patients were interviewed between August to October 2023 at a tertiary B-grade hospital's pelvic floor center in Shanghai. The data were collected through semi-structured in-depth interviews and analyzed using content analysis to identify and refine themes.

Results: The experiences of urinary incontinence in patients can be categorized into four main themes: (1) Daily life disturbances (including 4 sub-themes: sleep disorders, fluid intake restriction, travel inconvenience, loss of sexual life); (2) Negative emotional experiences (including 4 sub-themes: perceived discrimination, concerns about recovery, loss of confidence in life, doubts about the surgical decision); (3) Social withdrawal (including 2 sub-themes: reduced desire for social interaction, decreased ability to socialize); (4) Limited support obtained (including 4 sub-themes: reliance on personal experience, seeking help from relatives and friends, difficulty discerning online information, lack of professional guidance).

Conclusion: Postoperative urinary incontinence in prostate cancer patients presents a multidimensional experience. Healthcare professionals need to pay attention to these patients' daily life, psychological state, and social interactions. Integrating various resources to provide professional support and rehabilitation guidance is crucial.

Keywords: prostate cancer, qualitative research, radical prostatectomy, urinary incontinence, patient experience

Introduction

Urinary incontinence stands out as a particularly debilitating side effect of radical prostatectomy, despite advances in surgical techniques.^{1–3} It is worth noting that the usual time course of post-prostatectomy incontinence (PPI) is one of progressive improvement.⁴ The incidence rate of urinary incontinence within the early stage (3 months after surgery) is as high as 72%,⁵ and by the 12th month after surgery, the incidence rate of urinary incontinence ranges from 18% to 35%.^{6–8} Even if non-persistent, this early PPI poses substantial challenges to patients and impacts their overall quality of life.³

The condition transcends physical discomfort, encompassing profound psychological distress and social isolation.⁹ The stigma attached to incontinence often exacerbates feelings of embarrassment and self-isolation, leading to a cascade of emotional disturbances including anxiety, depression, and a diminished sense of self-worth.¹⁰ Moreover, the pervasive influence of PPI on social dynamics, personal relationships, and sexual well-being further compounds its impact, resulting in a comprehensive decline in the quality of life.¹¹ Consequently, PPI represents a complex health issue that demands a multifaceted approach to patient care, extending beyond medical treatment to encompass psychological and social support.³

The previous qualitative studies have explored the long-term life experience of patients after radical prostatectomy, with interviewed patients mainly from 1 year to 25 years post-surgery.^{12–16} At that time, the patients were in a stable state. In recent years, for patients with long-term urinary incontinence after surgery, the prevalent studies are focusing on decision-making for treatment of urinary incontinence.^{17–20} However, the qualitative studies on early postoperative patients predominantly concentrate on clarifying the knowledge gap of postoperative recovery,^{21,22} and did not explore the broader physical manifestations, psychological, and social implications caused by urinary incontinence at this changing stage.^{14,23} This lacuna in research fails to account for the comprehensive patient experience, particularly the emotional and mental health challenges posed by early PPI. The current literature inadequately addresses how patients cope with the daily challenges of living with PPI early after surgery, their strategies for managing the condition, and the efficacy of various support mechanisms.²⁴ There exists a critical need for research that not only documents these aspects but also evaluates the effectiveness of coping strategies and support systems.²⁵ Such an exploration is pivotal for enhancing patient care, developing targeted interventions, and ensuring a holistic approach that addresses both physical and psychosocial aspects of PPI.

In response to these gaps, our study employs a descriptive qualitative research methodology,²⁶ aiming to provide an in-depth examination of the experiences and needs of patients with early urinary incontinence following radical prostatectomy for prostate cancer. This study is designed to bridge the existing gaps in the literature by exploring the multifaceted dimensions of early PPI – its physical, psychological, and social aspects. By focusing on patient narratives, this research intends to unveil the complex nature of PPI, contributing significantly to the body of knowledge on comprehensive patient care strategies. It seeks to offer insights for the development of more effective, holistic interventions, ensuring that patient care encompasses not only the physical but also the emotional and social aspects of well-being.

Methods

Study Design

This research employs a descriptive qualitative study design.²⁷ This methodology is specifically chosen for its efficacy in capturing the nuanced experiences and perspectives of individuals in depth. It is particularly suitable for understanding the complex personal and psychosocial dimensions of living with post-prostatectomy incontinence (PPI).

Participants

The participants were identified at the pelvic floor center of Shanghai Fifth People's Hospital, Fudan University, where they received electrical stimulation treatment for urinary incontinence. Shanghai Fifth People's Hospital, Fudan University is a tertiary B-grade hospital, which is considered the second-highest level among tertiary hospitals and is renowned for its expertise in treating pelvic floor dysfunction diseases. The researchers conducted face-to-face recruitment and screening of patients who had undergone radical prostatectomy, using the International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF). The researcher provided verbal information about the study to patients identified as having urinary incontinence, inquired about their willingness to participate in the interview, and subsequently compiled a list of potential participants. Inclusion criteria include a pathological diagnosis of prostate cancer, continent before surgery, having undergone radical prostatectomy, experiencing urinary incontinence regardless of its severity (a score of ≥ 3 on the ICIQ-SF), being aged ≥ 18 years, having the ability to communicate and express oneself, and being aware of one's own disease diagnosis. Exclusion criteria include immobility and a history of urinary incontinence surgery. After analyzing the inclusion and exclusion criteria, 33 men were identified as eligible to participate in the study. Purposive sampling was then used to select participants,²⁸ based on the principle of maximum variation in terms of the type, duration, and severity of urinary incontinence. Of the 25 eligible patients invited to participate, 3 declined due to busy schedules, resulting in a total of 22 patients interviewed. The study's sample size was determined by data saturation, and we followed the principles stated by Hennink et al for determining saturation in qualitative research.²⁹ After analyzing 20 interviews, data collection was stopped when no new codes or themes emerged from 2 consecutive additional interviews, resulting in a total of 22 patients interviewed.

Data Collection

The interview outline was initially developed based on a literature review^{14,23,30,31} and the study's objectives, and then revised based on feedback from two pelvic floor rehabilitation therapists and a clinical nursing expert. Two patients were pre-interviewed to refine the interview outline. The final interview questions included: (1) How has your urinary incontinence changed since your surgery? What are your feelings about this? (2) How has urinary incontinence impacted your life? Please provide examples. (3) What difficulties have you encountered in managing urinary incontinence, and how have you dealt with them? (4) What kind of support and help do you wish to receive for urinary incontinence? Data were collected face-to-face in a semi-structured format by the first author of this study, a graduate student in nursing who had received intensive training before conducting the interviews. The interviewer had no previous relationship to the participants and were introduced to them as a nurse trainee. Each interview was a single session performed in private at the pelvic floor center. The interviews lasted for 45–60 min and were recorded by a voice recorder. Additionally, the interviewer took notes concerning the participants' behavior and non-verbal expressions.

Data Analysis

In this descriptive qualitative study, the data analysis process will be comprehensive and systematic,³² employing NVivo 20 software for efficient management and analysis of qualitative data. Initially, the research team will anonymize and code the interview data, and then thoroughly immerse themselves in the analysis. This immersion involves repeated listening to audio recordings and reading transcripts to identify key phrases and statements, which are then labeled as initial codes. Following this, these initial codes will be examined for emerging patterns and relationships to form potential themes, a process central to qualitative analysis. Themes, representing core ideas or concepts across multiple data points, are refined through a careful review of the original data and collaborative team discussions, ensuring they accurately reflect participants' experiences. The final stage involves the contextualization and interpretation of these themes within the broader scholarly discourse on urinary incontinence and prostate cancer.

Rigor

In ensuring the rigor of our study, we meticulously evaluated the credibility, reliability, and transferability of our findings following guidelines.³³ For credibility, participants were involved in confirming the accuracy of the collected data, with an additional focus on recording non-verbal cues such as facial expressions and body language during interviews. To bolster reliability, the first author and the corresponding author independently analyzed the data, subsequently comparing and discussing their findings to reach a consensus. Finally, the transferability of the study was facilitated by providing detailed descriptions of the sample and the data collection context, allowing for the evaluation of the findings' applicability in similar settings.

Ethics Approval

This study complied with ethical principles and guidelines outlined in the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee of Shanghai Fifth People's Hospital, Fudan University (Ethical Approval Form No. 2023–129). Participants were provided with detailed information about the study's purpose, content, and methods, and informed consent was obtained, including the publication of anonymized responses.

Results

The age range of the study participants was 63 to 88 years, with the duration of urinary incontinence ranging from 1 to 20 months. Detailed participant demographics are presented in [Table 1](#). Analysis of the transcribed interviews revealed 4 main themes and 14 sub-themes (see [Table 2](#)).

Daily Life Disturbances

This theme captures the various ways in which urinary incontinence post-prostatectomy disrupts the routine activities of daily life, affecting the participants' overall quality of life.

Table 1 General Information of Respondents (n=22)

| ID | Age | Education Level (Years) | Marital Status | Duration of Urinary Incontinence ^a (Months) | Severity of Incontinence ^b | Type of Incontinence ^c |
|-----|-----|-------------------------|----------------|--|---------------------------------------|-----------------------------------|
| N1 | 63 | 7~9 | Married | 9 | Moderate | SUI |
| N2 | 71 | 7~9 | Married | 7 | Severe | SUI |
| N3 | 79 | 10~13 | Widowed | 4 | Mild | MUI |
| N4 | 66 | 7~9 | Married | 8 | Moderate | SUI |
| N5 | 64 | 10~13 | Married | 20 | Moderate | MUI |
| N6 | 69 | 7~9 | Widowed | 4 | Moderate | SUI |
| N7 | 69 | 10~13 | Married | 2 | Severe | MUI |
| N8 | 79 | 7~9 | Married | 8 | Moderate | SUI |
| N9 | 73 | 0~6 | Married | 2 | Moderate | SUI |
| N10 | 72 | 0~6 | Married | 18 | Mild | SUI |
| N11 | 66 | 0~6 | Married | 6 | Moderate | SUI |
| N12 | 78 | 10~13 | Widowed | 3 | Severe | SUI |
| N13 | 79 | >14 | Married | 3 | Moderate | SUI |
| N14 | 66 | 7~9 | Married | 17 | Severe | SUI |
| N15 | 78 | 10~13 | Married | 3 | Severe | SUI |
| N16 | 88 | >14 | Widowed | 6 | Severe | MUI |
| N17 | 68 | 10~13 | Married | 1 | Moderate | SUI |
| N18 | 70 | 7~9 | Married | 11 | Moderate | MUI |
| N19 | 69 | 7~9 | Married | 1 | Severe | SUI |
| N20 | 72 | >14 | Married | 5 | Moderate | SUI |
| N21 | 65 | 7~9 | Married | 12 | Moderate | MUI |
| N22 | 69 | 7~9 | Married | 10 | Moderate | SUI |

Notes: ^aThe duration refers to the length of time that patients have been experiencing urinary incontinence prior to the interview, which can be roughly estimated as the length of time since surgery. ^bAccording to the ICIQ-SF scores, incontinence severity is classified into three levels: Mild (≤ 7 points), Moderate (7–14 points), and Severe (≥ 14 points). ^cThe type of incontinence is categorized based on the answer to the fourth question of the ICIQ-SF questionnaire into Stress Urinary Incontinence (SUI), Urgency Urinary Incontinence (UUI), and Mixed Urinary Incontinence (MUI).

Table 2 Main Themes and Sub-Themes

| Main Themes | Sub-Themes | Quotes from Patients |
|-------------------------|--------------------------|--|
| Daily Life Disturbances | Sleep Disturbance | "I also can't sleep well at night. I have to get up every one or two hours." (N5) |
| | Fluid Intake Restriction | "I used to drink water continuously, but now I drink less to avoid leakage." (N22) |
| | Travel Inconvenience | "If I go out, I need to use the bathroom every hour. Last week, my daughter suggested going to a big supermarket to walk around, but halfway through, I had to find a bathroom and come back out. It's very inconvenient." (N12) |
| | Loss of Sexual Life | "We don't have sex anymore. We used to do it once a week, but now we can't. At our age, it doesn't matter much anymore." (N21) |

(Continued)

Table 2 (Continued).

| Main Themes | Sub-Themes | Quotes from Patients |
|--------------------------------|--|---|
| Negative Emotional Experiences | Perceived Discrimination | "Now with the summer, wearing less clothing, I'm afraid of leaking and being seen. It's distressing. I also worry that people might say, 'Oh, why do you smell so bad? Why are you even here?'" (N13) |
| | Concerns About Recovery | "Before the surgery, the doctor said it would get better in three months. Then they said six months, and now they're saying a year. Nine months in, my urinary control is still poor. When will I see an end to this?" (N1) |
| | Loss of Confidence in Life | "What's the point of living if I have to wear diapers all the time? Every day is a burden. I've just locked myself away at home, living a miserable existence." (N6) |
| | Doubts About Surgical Decision | "If I had known it would be like this, I wouldn't have had the surgery. They said it wasn't necessary to operate and that other treatments were available. I would definitely consider other options." (N4) |
| Social Withdrawal | Reduced Desire for Social Interaction | "I used to have a group of friends to dine with, to go on car trips and hang out. Now, we hardly meet. They know about my condition and occasionally check on me by phone. They invite me out, but I don't feel like it anymore. It's not like before." (N11) |
| | Decreased Ability to Socialize | "Before the surgery, I was often socially active, teaching classes, writing, speaking. Now, I can't do these things anymore. I just don't have the capacity for them." (N16) |
| Limited Support Obtained | Reliance on Personal Experience | "I use a plastic bag over my urethra and tie it up. When it fills, I empty it in the bathroom. It's a crude method, but it's all I can do." (N4) |
| | Seeking Help from Relatives and Friends | "When it gets too hot with the diaper, my wife suggests using sanitary pads (laughs). No one knows I use them; it's our little secret." (N1) |
| | Difficulty Discerning Online Information | "After the surgery, I often looked online about how long people live after such surgeries. Some say five years, six, seven. It's confusing. Everything on the phone is a mess." (N7) |
| | Lack of Professional Guidance | "The doctor just said to do anal exercises but didn't explain how. He just wrote it down briefly without much explanation." (N10) |

Sleep Disturbance

Many participants reported that symptoms such as urinary frequency and urgency led to difficulties in falling asleep, sleep interruptions, and delayed sleep times, causing significant sleep disturbances. This was a common issue that significantly impacted their nightly routines and overall well-being.

The problem is that I have to get up more often at night to urinate. It takes at least an hour to get back to sleep each time. Now I dare not go to bed early. If I do, I have to get up 5 times, even if I sleep late at around 11 pm, I still need to get up at least 3 times. (N3)

I also can't sleep well at night. I have to get up every one or two hours. (N5)

My sleep at night isn't good, mainly because I need to urinate. It can wake me up from deep sleep, and it takes about 10 minutes to fall back asleep after each time. Like last night, I got up 4 times. (N7)

Fluid Intake Restriction

Some participants mentioned that they reduced their daily water intake to control the symptoms of urinary incontinence, no longer drinking as freely as before.

I now consume less water. I used to drink a lot, but now I'm afraid of urinating too much. (N8)

I dare not drink as much water as before. I used to drink a lot every day, but not anymore. (N15)

I used to drink water continuously, but now I drink less to avoid leakage. (N22)

Travel Inconvenience

Many participants expressed that they had to constantly be aware of toilet locations when outside and frequently change incontinence pads, which significantly inconvenienced their mobility and travel.

If I have to go somewhere far, I dare not venture out. It's very inconvenient to find toilets outside. I haven't left my house in months. As soon as I step out, I leak with every step. Once, I had to return from the vegetable market to my home just after leaving my community because of leakage. (N2)

If I go out, I need to use the bathroom every hour. Last week, my daughter suggested going to a big supermarket to walk around, but halfway through, I had to find a bathroom and come back out. It's very inconvenient. (N12)

Loss of Sexual Life

Many participants mentioned that their sexual lives could no longer proceed as normal. Although they accepted this due to age, it was still felt as a loss and a source of regret.

Now I can no longer have a sexual life (laughs). At our age, we don't do it much, but we used to. Now we can't, but it doesn't have a big impact because of our age. Whether we do it or not doesn't matter much now. (N5)

I can't have a sexual life now. Honestly, at our age, it doesn't happen much. My wife also comforts me, telling me not to think about it at our age. I agree, there's nothing we can do. (N17)

We don't have sex anymore. We used to do it once a week, but now we can't. At our age, it doesn't matter much anymore. (N21)

Negative Emotional Experiences

This theme encompasses the various emotional challenges and psychological burdens faced by participants, highlighting the profound emotional impact of living with urinary incontinence following prostatectomy.

Perceived Discrimination

Many participants spoke about feeling stigmatized due to the odor of urine and leakage, leading to a strong sense of shame and embarrassment. This sub-theme reflects the social stigma and negative perceptions associated with incontinence.

When interacting with others, I'm afraid they'll smell the odor and look down on me. I change the incontinence pad several times a day. If you don't change, people will notice the smell and think you are unhygienic. (N10)

Now with the summer, wearing less clothing, I'm afraid of leaking and being seen. It's distressing. I also worry that people might say, 'Oh, why do you smell so bad? Why are you even here?' (N13)

If I go out and my pants get wet, people will say, 'What's wrong with this old man? Doesn't he know his own condition?' I don't want to be talked about like that. I just stay home. It's embarrassing and frustrating. (N18)

Concerns About Recovery

A majority of participants expressed significant anxiety about the recovery process from urinary incontinence, including uncertainties about the possibility and timeframe of recovery, and fears of worsening conditions.

Before the surgery, the doctor said it would get better in three months. Then they said six months, and now they're saying a year. Nine months in, my urinary control is still poor. When will I see an end to this? (N1)

I worry about whether the leakage will get worse over time, as it hasn't fully recovered yet. Maybe maintaining the current state is slightly better. If the muscles don't recover, they might slacken. I worry it might get worse. (N5)

I don't know if this problem (urinary incontinence) can be cured or not. It's been really bothersome. Some say it's a lifelong issue after surgery. It's always on my mind. (N11)

Loss of Confidence in Life

Many participants felt that living with urinary incontinence was meaningless, leading to a sense of hopelessness and despair about the future.

What's the point of living if I have to wear diapers all the time? Every day is a burden. I've just locked myself away at home, living a miserable existence. (N6)

I often think, 'Oh, my life has lost its meaning.' Sometimes I feel like living is pointless, and I'm just waiting to die at home. There's nothing I can do. (N9)

I told my wife I'd rather die early. It feels pointless to live like this, unable to go out or do anything. It's not about being busy; it's about having a meaningful life. (N14)

Doubts About Surgical Decision

Some participants regretted their decision to undergo surgery due to the severity and duration of incontinence, which exceeded their expectations.

If I had known it would be like this, I wouldn't have had the surgery. They said it wasn't necessary to operate and that other treatments were available. I would definitely consider other options. (N4)

I feel like the surgery wasn't necessary. If I had known the incontinence would be this severe, I definitely wouldn't have done it. There are other treatments, like laser or cryotherapy, that probably wouldn't have this side effect and would allow for a better quality of life. (N14)

Later, I started wondering if it was overtreatment. My tumor was in the early stage. Couldn't they just remove the affected part and preserve the rest? It would have been better for preserving function. (N19)

Social Withdrawal

This theme reflects the participants' retreat from social interactions and activities due to the challenges and embarrassments caused by urinary incontinence.

Reduced Desire for Social Interaction

Many participants reported a diminished interest in social activities due to the inability to enjoy them as they did before the onset of urinary incontinence.

I used to have a group of friends to dine with, to go on car trips and hang out. Now, we hardly meet. They know about my condition and occasionally check on me by phone. They invite me out, but I don't feel like it anymore. It's not like before. (N11)

I don't go out much anymore. I don't want to. I used to meet up with colleagues for a walk, sometimes walking up to ten thousand steps, rain or shine. Now, when they invite me, I refuse. I've given up drinking and smoking, it's just not fun anymore, so I stay home. (N20)

Decreased Ability to Socialize

Some participants mentioned a decline in social skills such as writing and public speaking after surgery, hindering their ability to participate in social events.

After retirement, I was quite active socially. Leaders used to call me for writing assignments or evening meetings. Now, I tell them I can't participate. I used to write things easily, but now my response is slower, I just can't write as I used to. (N13)

Before the surgery, I was often socially active, teaching classes, writing, speaking. Now, I can't do these things anymore. I just don't have the capacity for them. (N16)

Limited Support Obtained

This theme encompasses the challenges participants faced in obtaining support for managing their condition, reflecting a gap in the healthcare system in providing adequate guidance and resources.

Reliance on Personal Experience

Many participants expressed that they had to rely on their own life experiences for managing urinary incontinence due to a lack of professional guidance.

I use a plastic bag over my urethra and tie it up. When it fills, I empty it in the bathroom. It's a crude method, but it's all I can do. (N4)

I put paper in my diaper, and when it gets wet, I change it. It's the most convenient way. In this hot weather, it's unbearable. I cut the diaper in half and use only the front part. (N14)

Instead of wearing a paper diaper, which is stuffy, I use two towels in my underwear. I wash and sun-dry them for reuse. It's not as uncomfortable as the diaper. (N15)

Seeking Help from Relatives and Friends

Most participants mentioned relying on partners, children, and friends for information and support, but noted that the help they could provide was limited, especially in professional aspects.

When it gets too hot with the diaper, my wife suggests using sanitary pads (laughs). No one knows I use them; it's our little secret. (N1)

The doctor mentioned pelvic floor exercises, but I didn't know how. Someone in my community had recovered, so I asked him. He explained it as contracting and relaxing muscles. (N9)

After surgery, I didn't know how to do pelvic floor exercises. I was confused, so I asked my son. He wasn't sure either, so we looked it up online. (N14)

Difficulty Discerning Online Information

Some participants turned to the internet for information on recovery and prognosis, but struggled to determine the accuracy of the information they found.

After the surgery, I often looked online about how long people live after such surgeries. Some say five years, six, seven. It's confusing. Everything on the phone is a mess. (N7)

I saw something on my phone about pelvic floor exercises, like lifting the buttocks. At our age, we don't understand these things well, so I'm not sure if it's right. I just randomly searched online. (N10)

I searched on Baidu on how to control urinary incontinence quickly, especially now that it's getting hot, and I want to stop using diapers. (N15)

Lack of Professional Guidance

Many participants discussed not receiving adequate pelvic floor rehabilitation guidance from healthcare providers, leaving them feeling helpless in managing their urinary incontinence.

During outpatient visits, with so many people waiting, the doctor just briefly mentioned pelvic floor exercises. It's your problem if you don't understand. They want to see patients as quickly as possible. (N9)

The doctor just said to do anal exercises but didn't explain how. He just wrote it down briefly without much explanation. (N10)

When I was discharged, they hardly mentioned anything. No one talked about it until later. The doctor just said to try hard, but I didn't know how. He said to contract the anus, but I wasn't clear on how to do it. Proper guidance is necessary, how do I know if I'm doing it right? (N14)

Discussion

This study focused on men in the early recovery phase after radical prostatectomy, aiming to explore the experiences and challenges faced by this population. The first 3 months after surgery was an important period when men first face their surgery-related problems and try to cope with these problems.³⁴ Employing a descriptive qualitative methodology, the analysis revealed the physical, psychological, and social changes among this group of people, shedding light on the multifaceted impact of early postoperative urinary incontinence. The results underscore the significant daily life disturbances, negative emotional experiences, social withdrawal, and limited support available to these patients. This study stands out in its in-depth exploration of men in the early post-surgical period, particularly emphasizing areas previously underexplored in the literature, thereby highlighting its novelty and contributing unique insights to the field.

In this study, it was observed that postoperative prostate cancer patients encounter various daily life disturbances. These disturbances encompass disrupted sleep patterns, fluid intake concerns, travel difficulties, and a decrease in sexual activity. Notably, sleep disruption, primarily due to nocturia and urgency, was identified as a critical issue. Leng et al noted that such sleep disturbances could exacerbate urinary incontinence.³⁵ Moreover, about two-thirds of male urinary incontinence patients restrict their fluid intake due to incontinence concerns, potentially leading to complications like metabolic imbalance and urinary tract infections.^{36,37} Furthermore, the study highlights the travel inconvenience experienced by these patients, which suggests a persistent state of anxiety and practical challenges during travel.³⁰ This inconvenience is primarily attributed to the urgent need for patients to promptly locate a bathroom whenever they are out, a practice commonly known as “bathroom mapping”, which is especially prevalent among female patients with urinary incontinence.³⁸ Interestingly, a unique aspect of our study is the observed acceptance of reduced sexual activity among older patients. This finding, which differs from some Western cultural perspectives, may be influenced by a decline in sexual drive and traditional Chinese cultural views on sexuality in older age.³⁹ However, patients may suffer from both urinary incontinence and erectile dysfunction after surgery, which affects their sexual life.¹² Our study did not determine which factor primarily contributed to the patient's loss of sexual life.

This study highlights that prostate cancer patients post-radical prostatectomy experience a spectrum of negative emotional responses, corroborating the findings of Jarzowski et al.⁴⁰ These emotions predominantly stem from concerns about the recovery process, including uncertainties regarding the recovery timeline and extent, which profoundly impact mental health.⁴¹ Before the surgery, the patients were informed that urinary incontinence would gradually improve, but this process may be lengthy and gradual. In the early postoperative period, the patients' urinary incontinence is in a transitional stage. At this time, the patients pay special attention to the recovery process of urinary incontinence and are concerned about whether it will worsen or persist. Furthermore, feelings of pessimism and despair, akin to those reported by Recklitis et al,⁴² are common among our study participants. Such emotions can escalate to serious levels, potentially leading to suicidal thoughts. Notably, patients with early postoperative urinary incontinence in our study often regret their decision to undergo surgery. For early postoperative patients, their bodies are still in the recovery stage, and they are confronted with various postoperative complications and discomforts, particularly urinary incontinence, which can easily affect their emotions. Moreover, in the early postoperative period, patients tend to have high expectations for surgical outcomes. However, the discrepancy between the actual severity of urinary incontinence and their expectations may lead to disappointment and regret.⁴³

The study finds a significant decline in social activity post-surgery. Ettridge et al found that this reduction in social engagement is primarily attributed to several interconnected factors.⁴⁴ The embarrassment and shame associated with urinary incontinence lead to negative self-perception and a tendency to avoid public appearances.³⁰ Additionally, the practical challenges of travel significantly contribute to social withdrawal.¹⁰ The logistics of managing incontinence, coupled with the fear of accidents, make travel daunting, further curtailing social interaction. The cumulative effect of these factors results in a diminished role in social activities and reduced enjoyment.¹²

This study reveals a critical gap in the support system for prostate cancer patients post-surgery, as they predominantly rely on personal experience and informal support networks.⁴⁵ The lack of professional medical support, particularly in providing comprehensive information about potential side effects of treatment, leaves patients ill-prepared to manage postoperative urinary incontinence. This absence of preparation and guidance is a significant concern, as it not only affects the patients' ability to cope with the physical aspects of incontinence but also impacts their mental well-being and quality of life.⁴⁶ Moreover, the study points out that the deficiency in professional rehabilitation guidance and supportive care forces patients to resort to self-management strategies for their condition.³¹ The internet, recognized as a valuable resource, poses specific challenges that are particularly pronounced for older patients.⁴⁷ Older patients often encounter difficulties in verifying and interpreting the extensive and complex information available online.⁴⁸

The findings suggest that comprehensive postoperative urinary incontinence care should include not only physical rehabilitation, but also targeted psychosocial and information support to address the multifaceted needs of prostate cancer survivors experiencing urinary incontinence. Nurses, as key facilitators in patient care, can play a pivotal role in providing support and guidance, especially during critical periods such as the perioperative and recovery phases. Their involvement is crucial in enhancing patients' understanding of their condition and helping them develop effective coping strategies, thus improving their overall quality of life.

This research acknowledges several limitations that should be considered. Firstly, the small sample size may limit the transferability and generalizability of the study's findings. However, it is important to note that the focus of this study was on understanding experiences and narratives, rather than on generalizing the results to a broader population. Secondly, the study was conducted with patients from a single hospital in Shanghai, not including patients from other comprehensive hospitals. Another limitation is that we are not sure to what extent urinary incontinence affects patients' sexual life, as the loss of sexual life may be caused by erectile dysfunction, another complication of surgery. This limitation suggests that future research should broaden the scope of investigation to include a more diverse patient population, potentially from different geographical locations and healthcare settings, to enhance the robustness and applicability of the findings.

Conclusions

This study provides substantial information about the experience and struggles of patients with early urinary incontinence after radical prostatectomy. Utilizing a descriptive qualitative approach, it uncovered four key areas: daily life disruptions, emotional challenges, social withdrawal, and limited support. These findings contribute to a more nuanced comprehension of early post-prostatectomy urinary incontinence, highlighting the concerns about recovery and doubts about the surgical decision in patients with early urinary incontinence. While limited by its small sample size and regional focus, the study emphasizes the need for holistic care that addresses both physical symptoms and emotional-social well-being.

Acknowledgments

The researchers thank all the participants.

Funding

This work was supported by the Fudan-Fosun Nursing Research Fund [grant numbers FNF202240].

Disclosure

All authors declare that there are no conflicts of interest in this work.

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