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RESEARCH ARTICLE

Qualitative analysis of online discussion boards for male urinary incontinence after prostate treatment

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Abstract

Introduction: Though urinary incontinence (UI) after prostate treatment often contributes to emotional distress and significantly impacts quality of life, many patients do not discuss this condition with their physicians. We analyzed the patient perspective by examining online support group posts to gain insight into specific challenges associated with different UI management methods.

Methods: We examined discussion board threads from multiple patient-focused forums on experiences of UI due to prostate treatment (threads from January 2016 to January 2022). Principles of grounded theory in thematic analysis were used to analyze the threads.

Results: Three hundred and eighteen posts from 84 unique users were analyzed. Among users, 47 (56%) reported UI following radical prostatectomy (RP), 5 (6%) secondary to radiation therapy (RT), 12 (14%) after a combination of RP and RT, and 20 (24%) were ambiguous. UI management methods included pads/diapers/liners, condom catheters/external clamps, Kegels/pelvic floor physiotherapy, and surgical treatment (artificial urinary sphincter or sling placement). We identified challenges common to all management methods: "requires trial and error," "physical discomfort," and "difficult to be in public." Factors influencing management choices included the ability to "feel normal" and the development of a management routine.

Conclusion: The current study identifies opportunities for improved expectation-setting and education regarding post-procedural UI and its management. These findings can serve as a guide for providers to counsel patients on the advantages and disadvantages of UI management devices.

KEYWORDS

artificial urinary sphincter, condom catheter, prostatectomy, prostate cancer, urethral sling, urinary incontinence

1 | INTRODUCTION

Urinary incontinence (UI) after prostate treatment can contribute to emotional distress and significantly detract from quality of life (QoL)[1,2]. Though treatment options for UI can be highly effective, many men with post-prostatectomy incontinence find this condition difficult to discuss with healthcare providers[3,4]. Understanding the lived experience of men with incontinence after prostate treatment may

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reveal opportunities for improved patient communication and care.

Management options for male incontinence vary by symptoms and patient preferences. Conservative options include pads, special undergarments, liners, condom catheters, penile clamps, pelvic floor physical therapy (PFPT), biofeedback, and medical therapy[5]. Surgery, such as placement of a urethral sling or artificial urinary sphincter, is another option. Though guidelines of the American Urologic Association encourage discussion of the risks and benefits of these different treatment options, there are few research studies identifying the shared and unique challenges of each UI management strategy[2].

To understand patient experiences with these devices, we analyzed online discussion forums of men experiencing UI after treatments for prostate cancer. Our objective was to analyze unprompted patient perspectives and gain insight into specific challenges associated with UI management. By further understanding these issues, we aim to inform providers to ultimately help patients navigate the incontinence experience and choose the appropriate management strategy.

2 | MATERIALS AND METHODS

2.1 | Forum selection

We identified online patient forums using a Google search for the keywords "male urinary incontinence forums," "male urinary incontinence discussion boards," and "male urinary incontinence support groups." Three forums were selected: incontinencesupport.info (incontinencesupport.info/forum.htm, accessed March 25, 2022), patient.info (patient.info/forums/discuss/browse/urinary-incontinence-2362, accessed March 21, 2022), and csn.cancer.org (csn.cancer.org/search?query=incontinence&scope=site&source=community, accessed March 17, 2022). Discussion boards pertaining to patient experiences of UI due to prostate treatment with threads from January 2016 to January 2022 were selected for analysis. Based on previous studies, this time interval was chosen to ensure posts reflected the most current user experience[6]. Boards were excluded if outside the time criteria or if the discussed topics were not in the scope of our investigation (i.e., male UI not caused by prostate treatment). Users were not identifiable, and posts were publicly visible. This investigation received an exemption from the University of California San Francisco institutional review board.

2.2 | Individual users' database creation

Three analysts (authors: Architha Sudhakar, Jason L. Lui, and Christine Shieh) read every individual user's post to record pertinent demographic information. Forum users thought to be the same individuals, based on similar usernames or pertinent biographical details, were combined, and analyzed as a single user. Ninety-two individual users across all discussion boards were selected for analysis. Each user's incontinence etiology and most recent incontinence management method were recorded. Incontinence etiology was primarily classified as radical prostatectomy and/or radiation therapy, and hormone therapy status was noted. Incontinence management methods were organized into four categories: Surgical treatment, pads/diapers/liners, external clamps/condom catheters, and Kegels/PFPT. Management strategies were identified based on users' written descriptions.

2.3 | Document preparation

All threads were uploaded to the qualitative analysis software Dedoose 9.0.17 (SocioCultural Research Consultants, LLC) and linked to unique descriptors of incontinence management to identify management methods for analyses.

2.4 | Coding process

We utilized principles of grounded theory in thematic analysis to analyze discussion board threads[7]. First, open codes were generated and assigned based on specific language pertaining to users' experiences with incontinence management strategies. Axial codes were then created to establish links between related open codes. Finally, selective codes were created to unify axial codes and identify broad themes emerging from the data. Multiple codes were applied to the same excerpt when appropriate. One researcher performed the coding, and two researchers reviewed the dataset with the codebook and excerpts to ensure agreement with all assignations. Disagreements involving specific excerpts or code assignments were discussed between all three researchers and rectified by a fourth expert (Nathan M. Shaw, or Benjamin N. Breyer).

2.5 | Statistical analysis

A chi-squared test was run to compare likelihood of using particular incontinence management strategies in the RP group compared to RT or "combined" groups.

3 | RESULTS

We analyzed 318 posts from 84 unique users. Eighty users were men posting about their own incontinence, 5 were spouses, and 1 was a daughter

describing her father's experience. Forty-seven users (56%) reported incontinence following RP, 5 (6%) following RT, 12 (14%) after a combination of RP and RT, and 20 (24%) did not describe their intervention (Figure 1). We identified challenges common to all users regardless of management strategy as well as method-specific challenges (Table 1). Individuals undergoing RP utilized Kegels/PFPT at the highest rate of (18/47, $p = 0.027$), and individuals undergoing combined RP/RT treatment utilized pads/diapers/liners use most (8/12, $p = 0.003$).

3.1 | Shared management challenges

3.1.1 | Trial and error

Patients or their loved ones noted frustration with trying multiple versions of an incontinence product before finding an acceptable fit (Figure 1 and Table 1). This was particularly true among condom catheter users. As described by User 5: "It took a while to figure everything out and find what works best." Several patients noted being overwhelmed by the diversity in types of external catheter devices and their features. Others, however, saw the diversity as hope for finding the best match for satisfactory leakage control.

3.1.2 | Physical discomfort

Physical discomfort was mentioned by individuals in all management groups. Among those using pads/diapers/liners, bulkiness was cited as a source of bother: "These diapers and guards are so cumbersome: I can't button my trousers!", or "[I use] 8–10 diapers on … catheter-less days, each weighing around a half pound of urine." Individuals using clamps often described pinching discomfort from the device, sometimes leading to fear of unforeseen bodily harm: "It could cause untold vascular damage if left on a long time." Individuals employing Kegels exercises frequently mentioned sore muscles, and they too worried that the management strategies could injure their bodies, "[I] was told too much is not good either: The sphincter can tire easily, I guess."

Some patients undergoing artificial urinary sphincter (AUS))/sling surgery noted more post-surgical discomfort than expected. Swelling, pain, tenderness, and

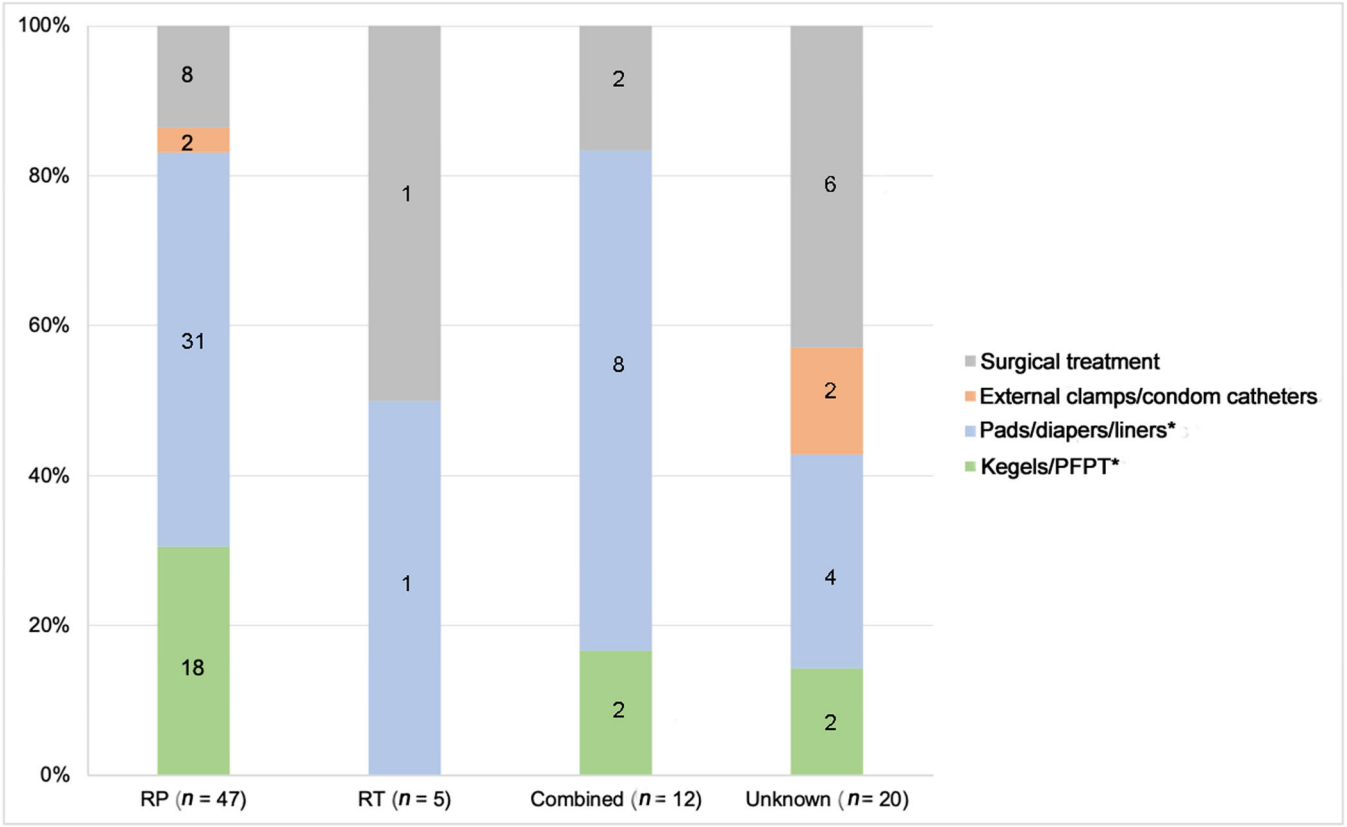

FIGURE 1 Total users by self-reported urinary incontinence (UI) management method and UI etiology. Individual users may be included in more than one incontinence management category. Numbers adjacent to each column represent no. cases mentioning the use of each particular management strategy. PFPT, pelvic floor physical therapy; RP, radical prostatectomy; RT, radiation therapy. * indicates statistical significance.

TABLE 1 Additional excerpts for shared and method-specific challenges, and reasons for choosing each management strategy.

A. Shared challenges		
1. Requires trial and error	1.1. External clamp/ condom catheter	"I recommend having your supplier provide samples to see which ones and which size works best for you."
	1.2. Kegels/PFPT	"I am on a second pelvic floor therapist to see if it helps. But to be honest, I feel they are a total waste of time."
2. Physical discomfort	2.1. Pads/diapers/liners	"At first, I tried pads and briefs but they quickly become soaked and irritate my penis and groin." "I would go through 6 to 10 heavy duty Depend pull-up per day and hated it because I could put on a new one; and 30 minutes later, have this wet thick mass between my legs." "I've tried other pads in my underwear including kids' diaper boosters, urinary pads, etc. But they seem uncomfortable and shift too easy in the underwear."
	2.2. External clamp/ condom catheter	"The clamp becomes uncomfortable after a short period of time and isn't really recommended for use at night." "Major issue for me is finding comfortable underwear to wear with the condom catheters." "Today for the first time tried a Cunningham clamp. Worked well, no leaks at all, but after a short while uncomfortable feeling, sometimes a urine surge from movement that would normally go into pad now feels kind of burning from being held in."
	2.3. Kegels/PFPT	"My Kegel muscle is sore from workout. The leaking continues."
	2.4. AUS/sling	"My dad wants it removed as he says its uncomfortable when sitting down but would have lived with this device inside had it worked." "For a week or so, it's difficult to walk normally. But you can shuffle."
3. Difficult to be in public	3.1. Pads/diapers/liners	"I tend to use the pads during the day because changing the briefs when out is not very convenient." "I thought I could handle this, but I have had to stop almost all activity and limit my time without a bathroom to change pads to an hour or so, as I have not been very good at predicting how much urine I will have." "The only semblance of socializing I do now are birthday parties, Christmas, and Thanksgiving get-togethers at my daughter's home. [...] I'm safe at home."
	3.2. Kegels/PFPT	"I still get depressed even from the mild leakage, because I hate being so dependent on the bathroom."
B. Method-specific challenges		
1. External clamp/condom catheter		"I'm incontinent and use external condoms with a urine collection leg bag during the day and larger night bag. It's not a perfect solution but keeps me dry 90+% of the time." "At times, I use a penile clamp during portions of the day. But due to significant frequency, this isn't always a great answer." "Adding water-proof tape also helps keep the condom on if you're having trouble keeping them on for 24 hours. And a Depends pad helps your confidence if the condom comes off." "They were terrible as the adhesive would not release. Some nights, I would spend 45 minutes working to remove the dang condom without tearing the skin."
2. Kegels/PFPT		"I have no real urges. It simply leaks whenever I move, bend, laugh, or even stand up." "The most frustrating thing for me is not knowing what the future holds." "[I leak] only under some conditions. Like getting off my indoor trainer bike after riding for maybe 70–80 minutes continuous, or heavy lifting." "I still don't see how the Kegels are helping. They just cause the urine that has been released from the bladder to be expelled through the urethra. So, this leakage still occurs."
3. AUS/sling		"I've needed other surgeries, and at 70, I am getting to the age where I must prioritize what surgeries are more important." "For the last 3 years or so, I am having some leakage when I sit in certain positions or ride a bike." "You will have no bladder control until the doctor activates the AUS, usually in 6 weeks." "Just thinking about such a procedure makes me shudder. I hope I don't have to worry about it for a few years." "I ask each and every member of the operating medical team every time that they approach me for any reason, while I'm on the gurney: 'What implant do I have that is important for you to know about?'"

Abbreviations: AUS, artificial urinary sphincter; PFPT, pelvic floor physical therapy.

ecchymosis were identified as bothersome consequences of surgery. One user warned others that "surgery may not be as easy as some say it was. There is lots of swelling and discomfort for several weeks afterwards, perhaps even months." One AUS recipient noted the impact of these discomforts on daily life, "I have to be careful getting in and out of the car, and some seats are very uncomfortable. It even affects my stride when I walk." In other cases, the post-surgical discomfort was seen as an acceptable consequence of overall positive experiences with UI surgery, "the pain and inconvenience is far better than dealing with diaper or condom catheters and leg bags."

3.1.3 | Public visibility

Many individuals were concerned with the visibility of their condition in public. "Wearing shorts will be a challenge," described one user with a condom catheter bag. For some writers, the self-consciousness was present even in health care settings: "I still get embarrassed when a new health professional sees me in a diaper [...]. When I had my back surgery [...] I had to be changed twice by female nurses. You can imagine my embarrassment when I told them I was wet and needed a change." Difficulties finding public places to change and clean up led to feelings of social isolation in many accounts: "I cannot see removing shoes, trousers, etc. in public bathroom to change pull-ups." In some instances, the concern about public visibility made individuals "scared to leave the house."

3.2 | Method-specific management challenges

Many complaints were specific to the incontinence device used (Table 1B).

- Pads/liners: Frequent pad changes were a common complaint among individuals pursuing this maintenance strategy. The cost of the pads was also noteworthy, as one user described spending "over $2,000 out-of-pocket money" in a 10-month period.
- Condom catheters: Several condom catheter users complained about the adhesives, which are used to fit the condom to their external genitalia. The inconsistency of the fit was a challenge, as one user questioned, "will it stay on for 24 hours at a time without leaking or coming off"? Others described skin irritation from the adhesives, needing vacation period from products to allow for recovery: "[I] go without catheter for a day or two each week" to "dry out" and allow "[my] skin to recover."
- Kegels: The slow and non-linear course of improvement among Kegel users caused disappointment for some. In particular, the necessity of maintenance exercises, even after many years of gaining continence, caused frustration. One user described that "you tend to make quick gains, then hit a ceiling and hover there for months waiting for a breakthrough."
- Artificial sphincter: Some surgical patients expressed concern over the lack of familiarity among healthcare workers regarding the AUS: "the scary aspect [...] has been the surprising number of doctors and nurses that have had no idea what an AUS is or how it works [...]." Surgical patients also noted dissatisfaction due to sudden, permanent device malfunction. One user noted that the "AUS worked beautifully for 17 months, then the reservoir developed a pinhole-sized leak, and all of the hydraulic fluid escaped".

3.3 | Factors in choosing a management strategy

Many forum users had tried multiple devices, and their comments identified factors that influenced their ultimate management choice.

3.3.1 | Return to normal

Improvement in quality of life, specifically the ability to live a "normal" life, was a recurrent factor in patients' choice of UI management strategy. One user noted satisfaction with AUS, stating, "[...] it has given me a large part of my life back", while another user recommended external clamps, stating, "I think you will find you can live a fairly normal social life." Users describing tools that made their lives more "normal" expressed satisfaction with their UI management.

3.3.2 | Routine and acceptance

For some men living with UI, the non-surgical options eventually became routine and, ultimately, acceptable. For example, one pad user stated: "After time, they become your new normal" and a clamp user stated other, "after a few painful starts, I eventually mastered a routine for comfortably using it." As described by another gentleman, developing familiarity with products ultimately led to satisfaction: "It took a while to figure everything out and find what works best but by 3 months out had a routine that has worked very well."

4 | DISCUSSION

This qualitative study investigated the voices of anonymous men with UI after prostate treatment to understand the challenges and advantages of different

	Requires trial and error	Physical discomfort	Difficult to be in public
Condom catheters	"I was amazed to find that there are multiple sizes … and multiple manufacturers with different brands, each with different features."	"Major issue for me is finding comfortable underwear to wear with the condom catheters."	"Wearing shorts will be a challenge but there are solutions for that also."
External clamp	"I tried several clamps but recently found the new Lunderg Confidence clamp to be the most effective clamp for me."	"I tried the clamp but after a few hours I had to remove it as it burned and was quite uncomfortable"	
Pads/diapers/liners	"I am still experimenting with different diaper brands. Size-wise I am just between the medium or large."	"These diapers and guards are so cumbersome: I can't button my trousers! I think that is what is adding to scrotum discomfort."	"I'm getting through incontinence pads at quite a rate and scared to leave the house."
Kegels/PFPT	"I must have at least 25 difference pelvic floor exercises by now."	"I was told to much is not good either, the sphincter can tire easily I guess."	"I'm still going through four to five Depends Undergarments a day … I'm 60 years old and starting to turn into a semi-recluse because of this."
AUS		"There is still the discomfort of the device being in my groin. I have to be careful getting in and out of the car […]. It even affects my stride when I walk."	

FIGURE 2 Sample excerpts of shared and remedy-specific themes for challenges in the management of post-prostatectomy urinary incontinence in men. AUS, artificial urinary sphincter; PFPT, pelvic floor physical therapy.

incontinence management strategies. We identified universal challenges: The need for trial and error with different devices, physical discomfort, and public visibility (See Figure 2). Certain disadvantages were device-specific, such as the cost of pads, the unpredictable failure of AUS, or the partial effectiveness of Kegel exercises. Factors that led to user satisfaction included a "return to normalcy" and the development of a routine with the devices.

The current study is unique in that patients' opinions were anonymous. Certain users described experiencing shame around their incontinence, even in front of healthcare workers. While anonymous qualitative research precludes the opportunity for rapport-building with participants, the anonymous nature of this kind of study may allow individuals to honestly communicate about personal challenges that can be difficult to discuss openly[8]. This style of forum-based analysis has been used to study the patient experiences in other sensitive conditions such as breast cancer[9]. In the urologic sphere, anonymous patient opinions have been surveyed to understand intimate issues of individuals with urologic congenitalism such as sexual desire, caregiver burnout, mental health, and access to medical care[10–13]. The current study builds on this style of work to understand the challenges of managing male UI.

Our findings highlight the importance of patient counseling before and after prostate treatment, particularly regarding expectation setting for UI. As recommended by the American Urologic Association practice guidelines, physicians should discuss the risks, benefits, and expectations of different UI management strategies with patients experiencing UI after prostate cancer treatment[2]. This study identifies subjects to discuss: Patients should anticipate challenges with physical discomfort, public visibility, and a period of "trial and error" with each UI management strategy. The challenges of the specific UI management approaches should also be discussed.

For patients undergoing AUS, anticipating bruising and swelling should be discussed explicitly. This is exemplified by one patient who explained, after his second AUS placement, "this time the post surgery pain and scariness was much less since I had experienced it before". Perhaps the "pain and scariness" of the first AUS placement could have been alleviated with proper counseling. Patients undergoing AUS placement should also be informed of the possibility of sudden malfunction with need for device replacement.

Analysis of anonymous patient posts shed light on important counseling factors for the other UI management strategies as well. Patients using pads and liners cared about the frequent need to change the devices and the cost of using so many supplies. Condom catheter users consistently described the irritation of adhesives and the difficulty of removing the device. Men who used a clamp often complained of the discomfort of the device and the challenges with urinary frequency and urgency. Finally, those who underwent PFPT described issues of pelvic floor soreness and overuse, sometimes describing disappointment that the work did not resolve the incontinence. By informing patients of the challenges of different management options, the urologist can help tailor UI treatment to the unique preferences of each patient and potentially decrease patient anxiety with UI treatment.

5 | LIMITATION

Posts from these forums may not represent the general population of men living with incontinence, and it is possible that despite our user identification strategies, some voices may be over-represented. These forums do not necessarily follow patients longitudinally, and user experiences with devices may change over time. Despite these limitations, we believe this is a meaningful study that adds to the scarce literature on the patient experience of UI related to prostate cancer treatment.

6 | CONCLUSION

Our study reveals that men with incontinence face diverse challenges in managing UI, often specific to the chosen strategy. However, forum users identified a set of shared challenges irrespective of their primary management method—requiring trial and error, physical discomfort, and difficulty being in public—and several challenges that were unique to specific UI management tools. As many patients experiencing UI are embarrassed to discuss their issues with their medical team, these results provide insight into challenges faced by men with incontinence and how urologists may best provide support and education.

AUTHOR CONTRIBUTIONS

Adrian Fernandez was responsible for the conceptualization, project administration, and both the preparation of the original draft and its subsequent review and editing. Behzad Abbasi contributed to the conceptualization, prepared the original draft, reviewed and edited the text, and also took part in investigation and data curation. Architha Sudhakar participated in the conceptualization, prepared the original draft, and was involved in investigation and data curation as well. Christine Shieh focused on formal analysis and investigation. Lindsay A. Hampson handled methodology, reviewed and edited the text, conducted investigations, and provided supervision. Jason L. Lui and Umar Ghaffar were both tasked with formal analysis and investigation. Hiren Patel's contributions included methodology, writing reviews and edits, conducting investigations, and providing supervision. Nathan M. Shaw's contributions included conceptualization and supervision. Benjamin N. Breyer played a multifaceted role involving methodology, writing reviews and edits, investigation, supervision, and conceptualization.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data is publicly available on the websites disclosed in the manuscript.

ETHICS STATEMENT

This study analyzed materials from anonymous bloggers whose writings are in the public domain, and therefore informed consent was not obtained.

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