

UCSF

UC San Francisco Previously Published Works

Title

How older men live with stress urinary incontinence: Patient experience and navigation to treatment

Permalink

<https://escholarship.org/uc/item/4rx8z8rc>

Journal

Neurourology and Urodynamics, 43(1)

ISSN

0733-2467

Authors

Shaw, Nathan M
Breyer, Benjamin N
Walter, Louise C
[et al.](#)

Publication Date

2024

DOI


10.1002/nau.25325

Copyright Information

This work is made available under the terms of a Creative Commons Attribution License, available at <https://creativecommons.org/licenses/by/4.0/>

Peer reviewed

How older men live with stress urinary incontinence: Patient experience and navigation to treatment

Nathan M. Shaw^{1,2}  | Benjamin N. Breyer^{1,3} | Louise C. Walter^{4,5} |
 Rebecca L. Sudore^{4,5} | Anne M. Suskind¹  | Caitlin Baussan¹ |
 Kathryn Quanstrom¹ | Isabel E. Allen³ | Matthew R. Cooperberg^{1,6} |
 Dan Dohan⁷ | Lindsay A. Hampson^{1,6} 

¹Department of Urology, School of Medicine, University of California San Francisco, San Francisco, California, USA

²Department of Urology, MedStar Georgetown, Washington, District of Columbia, USA

³Department of Epidemiology & Biostatistics, School of Medicine, University of California San Francisco, San Francisco, California, USA

⁴Department of Medicine, School of Medicine, University of California San Francisco, San Francisco, California, USA

⁵Department of Medicine, San Francisco Veterans Affairs Medical Center, San Francisco, California, USA

⁶Department of Surgery, San Francisco Veterans Affairs Medical Center, San Francisco, California, USA

⁷Institute for Health Policy Studies, University of California San Francisco, San Francisco, California, USA

Correspondence

Lindsay A. Hampson, Department of Urology, University of California San Francisco, San Francisco, CA, USA.
 Email: Lindsay.Hampson@ucsf.edu

Funding information

Doris Duke Charitable Foundation (PI: Hampson), Grant/Award Number: CTSI-UL1 TR001872; Claude D. Pepper Older Americans Independence Center UCSF Research Education Component Scholar Award (PI: Hampson); National Institute on Aging (PI: Sudore), Grant/Award Number: K24AG054415; NIH/NIDDK (funding: Hampson), Grant/Award Number: K12K083021; National Institute on Aging GEMSSTAR (PI: Hampson), Grant/Award Number: 1R03AG064372-01; San Francisco Veterans Affairs Medical Center (Hampson, Cooperberg, Sudore, Walter)

Abstract

Objectives: To explore the context in which older men navigate treatment for stress urinary incontinence (SUI) following prostate surgery by characterizing lived experience of men with symptomatic SUI.

Subjects/Patients and Methods: Mixed method study using surveys and semistructured interviews to examine a cohort of men who underwent evaluation for treatment of postprostatectomy SUI.

Results: Thirty-six men were interviewed after consultation for SUI and 31 had complete quantitative clinical data. Twenty-six underwent surgery and 10 chose no surgical intervention. In qualitative interviews, respondents experienced substantial decline in quality of life due to incontinence citing concerns associated with use of pads and worrying about incontinence. Most patients reported “workarounds”—efforts to mitigate or manage incontinence including Kegels, physical therapy, and garments. Participants also reported lifestyle changes including less strenuous physical activity, less sexual activity, and/or fewer social gatherings. Patients then described a “breaking point” where incontinence workarounds were no longer sufficient. After seeking evaluation, men described challenges in exploring treatment for SUI, including access to care and provider knowledge of treatment options.

Abbreviations: AUS, artificial urinary sphincter; QoL, quality of life; SUI, stress urinary incontinence.

Clinical Trial Registration: The study is IRB approved qualitative interviews not representing a clinical trial.

Conclusion: In a novel study of patients living with SUI a predictable lived experience was observed that culminated in a desire for change or “breaking point.” In all men, this led to treatment-seeking behaviors and for many it led to SUI intervention. Despite effective treatments, patients continue to meet barriers gaining access to SUI evaluation and treatment.

KEYWORDS

artificial urinary sphincter (AUS), lived experience, male stress incontinence, prostate cancer, qualitative

1 | INTRODUCTION

Following surgical treatment for prostate cancer, 10%–30% of men will have urinary incontinence that persists 1 year following prostatectomy, at which time continence is known to plateau.^{1–3} Even with advances in prostate surgery this rate has not substantially decreased and data continue to suggest that older, comorbid men are more likely to experience stress urinary incontinence (SUI) postoperatively.¹ Furthermore, with treatment of high-risk prostate cancer, radiation after prostatectomy can often lead to worsening of incontinence and overall urinary function.^{4,5} SUI is known to contribute to poorer quality of life (QoL), embarrassment, shame, social isolation, and depression.^{6,7}

Despite the number of men living with SUI; only 3%–6% of affected men undergo surgical treatment of postprostatectomy SUI.^{8,9} Those men that do undergo surgical treatment for SUI have been shown to have high patient satisfaction and durable improvements in QoL.^{10,11} Additionally, men who delay or choose not to undergo treatment for SUI have significantly higher levels of decisional regret compared to those who undergo treatment.¹² There is therefore a substantial number of men living with untreated incontinence following treatment for prostate cancer whose lived experience is incompletely understood. With reliable, safe options to address SUI—a major QoL issue—why are so few men receiving treatment?

Existing data are largely derived from data sets examining cohorts of men who undergo treatment for prostate cancer or specific treatment for SUI. The population of men living with SUI who seek treatment and choose not to undergo surgery is relatively understudied. To our knowledge this is the first study which focuses on the elucidating the patient-reported experience of postprostatectomy SUI. The objective of this study is to describe the lived experience of older men with SUI and to better understand why and how men seek care to help guide clinical outreach and counseling and improve access to care.

2 | SUBJECTS/PATIENT AND METHODS

2.1 | Study design and patients

Mixed methods analysis was employed to understand the experience of men living with postprostatectomy urinary incontinence.

2.2 | Recruitment

Individuals who underwent consultation and/or surgery for male SUI between June 2015 and March 2020 at University of California, San Francisco were called by phone to assess their interest in participating in the study. Informed consent was then obtained before a qualitative semistructured interview. Recruitment aimed to include equal proportions of men who chose each surgical treatment for male SUI: Artificial Urinary Sphincter (AMS 800™ Boston Scientific Marlborough; CPT 53445) and male sling (AdVance XP™ Boston Scientific Marlborough; CPT 53440). An equal proportion of patients who chose no surgical treatment were recruited. Participants were offered a \$20 Amazon gift certificate after completion of the interview. Ethical approval was granted by the Institutional Review Board at the University of California, San Francisco (REF#:s: 17-23374 and 19-28455).

2.3 | Data collection

Semistructured interviews were performed using an interview guide (Supporting Information S1: Appendix 1). The interview guide was updated iteratively by two team members (K. Q. and L. H.) if any novel important themes or topics of interest arose during interviews. All interviews were conducted by trained study personnel (K. Q., C. B., and L. H.) via phone and were ~30 min in length.

Participants in the quantitative portion of the study additionally had demographic, clinical, and patient reported outcome measures (PROMs) collected via chart review and telephone survey.¹³

2.4 | Data analysis

After complete transcription of all interviews, four coders (authors: N. S., C. B., I. A., and L. H.) read all transcripts for themes that emerged using Dedoose data (Socio-Cultural Research Consultants; LLC). The initial coding scheme was derived from prior thematic analyses with first pass of all available transcripts with periodic review by all coders.^{14,15} After identification of major themes, N. S. and L. H. recoded the transcripts, comparing, discussing, and agreeing on each code throughout the transcripts. Emergence of new codes or trends prompted a review of all transcripts for the same. After complete review, a final expert (author: D. D.) guided organization of themes. This iterative process was repeated until all themes were saturated.

3 | RESULTS

A total of 36 semistructured interviews were completed between May 2017 and May 2018. Complete interview and quantitative data were available on 31 patients (AUS [12], sling [9], and 10 subjects without intervention). Participants' average age was 74 with median of 4 pads per day among those with complete data (Table 1). The thematic qualitative analysis included all 36 participants, and mixed methods included the 31 participants with complete data. Over the course of the interviews a pattern of how patients experience SUI emerged: (1) Men initially experienced an impact on their QoL from SUI and then employed mitigation efforts or “work arounds” to manage these QoL changes. (2) Nearly all men experienced a breaking point where work arounds no longer mitigated the QoL changes and led them to seek treatment evaluation. (3) After this breaking point there was tremendous variability in experience of navigating treatment options; many men struggled to be seen by a Urologist to discuss SUI treatment options, and others were inappropriately told there were no options for treatment.

3.1 | Impact on QoL

Participants noted SUI-induced changes in their the QoL following prostate cancer treatment. Nearly all men

explicitly mentioned the detrimental impact of SUI on their QoL: “My whole life was dominated by--all I could think about was dealing with pads” (participant 14; hereafter “14”) (Table 2.1.1). Participants also noted drastic changes in desire to attend social gatherings: “you can't go out in public”(8) (Table 2.1.2). Others noted embarrassment, depression, anger, and avoidance of otherwise desirable activities (e.g., sex) due to SUI (Table 2.1.3–6). For many men, the personal severity of the QoL change did not necessarily correlate with objective measurements such as pads per day or PROMs questionnaires (Figure 1).

As men discussed their struggles with SUI and resultant changes to daily routine and QoL, another theme emerged—how men included others in their lived experience of SUI. Nearly one-third of our respondents kept their incontinence very private, sharing their experience with no one, not even intimate partners. Others shared their experiences with family, friends, and support groups (Table 2.1.7–9). Notably, all patients save one who kept their incontinence private chose to undergo surgical intervention with AUS or sling.

3.2 | Incontinence mitigation—“work arounds”

After an initial adjustment period, men living with SUI often found incontinence workarounds that mitigated the impact on their QoL. Some men referred to this as their “new normal.” Workarounds included treatments such as Kegel exercises, medications or pelvic floor physical therapy, incontinence management systems (pads, condom catheter, AFEX AktivCare®, etc.), and daily lifestyle adjustments. In the interviewed cohort, nearly all men explicitly mentioned Kegels, pads, and pelvic floor physical therapy. Compared to mentions of Kegels or pads fewer men discussed condom catheters, medications, and other collection systems (Table 2.2.1). Notably, all men noted changing their lifestyle to address incontinence including limiting or changing exercise (Table 2.2.2).

The period of mitigation attempts was the most variable stage of the patient lived experience amongst the cohort; both in terms of how patients discussed their lives and how long they chose to live in this “new normal.” To contextualize the variability of this stage, the time of onset of SUI to surgical consultation among our cohort ranged from 54 days to over 20 years (Figure 2). Some of this range may be explained by how men utilized workarounds and what impact that had on their QoL. Some participants noted that this “new normal” was acceptable and they never sought (or were never offered)

TABLE 1 Patient characteristics and treatment choice.

Patient	Age	Garment per day	CCS	Bother ^a consult	ICI-Q total consult	Bother ^a current	ICI-Q current	PROMIS (physical health)	PROMIS (mental health)	Treatment
1	74	0 ^a	3	10	21	2	7	46.6	51.6	AUS
2	65	4	-	-	-	-	-	-	-	Sling
3	72	4	4	7	18	2	6	41.4	48.2	AUS
4	78	10	5	3	12	1	6	37.7	53.1	AUS
5	80	2	4	4	9	0	0	48.2	51.6	Sling
6	80	5	-	-	-	-	-	-	-	AUS
7	73	8	7	10	21	4	10	57.9	57	AUS
8	74	5	-	-	-	-	-	-	-	AUS
9	66	5	-	-	-	-	-	-	-	AUS
10	63	3	4	-	-	-	-	-	-	Sling
11	82	10	4	4	15	3	11	46.8	46.6	AUS
12	72	3	2	10	19	8	14	62.2	54.6	Sling
13	-	-	-	-	-	-	-	-	-	AUS
14	74	9	4	9	18	3	8	62.5	63.6	Sling
15	75	2	3	9	20	3	9	46.9	53.1	Sling
16	82	6	4	7	18	1	7	57.6	60.6	AUS
17	71	10	5	8	16	1	5	49.2	58.7	AUS
18	88	1	5	1	12	0	3	54.4	61.8	Sling
19	68	2	2	5	13	2	7	61.6	67.6	Nonoperative
20	74	7	3	8	17	2	9	54.5	63.6	Nonoperative
21	71	1	5	4	11	4	8	53.5	53.3	Nonoperative
22	70	4	2	8	16	1	5	57.8	56.8	AUS
23	79	2	3	3	11	1	6	41.4	38	Sling
24	78	1	3	0	8	2	9	62.2	58.3	Nonoperative
25	66	0 ^a	2	8	15	8	15	54.7	48.2	Nonoperative
26	82	2	6	3	10	3	8	44	53.1	Nonoperative
27	73	3	3	9	18	8	14	40.4	37.4	Nonoperative
28	83	2	5	5	13	5	14	46.3	47.3	Nonoperative
29	75	5	3	10	21	3	9	61.6	60.1	Sling
30	72	2	5	7	15	5	13	48.2	45.7	Nonoperative
31	68	2	9	2	6	0	9	39.5	43.3	Nonoperative
32	76	4	5	8	17	1	6	44.3	53.1	Sling
33	78	4	7	10	21	0	0	51.5	54.6	Sling
34	81	7	4	6	17	0	0	62.2	63.6	AUS
35	81	2	6	3	11	1	4	67.7	67.6	AUS
36	71	5	6	9	20	6	12	42.1	48.3	AUS

Note: "Consult" time point was initial visit. "Current" time point was at the time of structured interview (postoperative for those who underwent intervention). ICIQ: Validated instrument to assess symptom severity and quality of life (QoL) due to SUI. Score range 0–21, 21 being highest impairment. PROMIS: Global health (mental health) *T* score.

Abbreviations: CCS, Charleston comorbidity score; SUI, stress urinary incontinence.

^aAssessed based on "To the best of your recollection, at that time, overall how much did leaking urine interfere with your everyday life?" Choice between 0 (not at all) and 10 (a great deal).

TABLE 2 Selected participant interview quotes by theme.

Patient lived experience theme	Selected quote or excerpt
2.1 Impact on quality of life	
2.1.1: Detrimental QoL	“My whole life was dominated by—all I could think about was dealing with pads” (14)
2.1.2: Social isolation	“You can just imagine you had no control. I mean you can't go out in public, you can't do anything”(8)
2.1.3: Anger	“Emotionally my response is absolute frustration and something like anger. I don't know who to be angry at, so it's kind of loose anger” (15).
Activity avoidance	
2.1.4 Sex	When asked about the relationship between sex life and incontinence: “No, I wouldn't say [sex and incontinence] were separate at all. Oral sex is impossible for me to receive while I have urinary incontinence. I mean only in the most bizarre circumstance would that be possible, right” (22).
2.1.5 Exercise	“No, not really. I mean it was there. Certainly, if I had a glass of wine or glass of beer it was more. If I was exercising there was some leakage, but no it didn't really change much” (24).
2.1.6 Social avoidance	“It was terrible. I mean you know, I didn't want to see anybody, I didn't want to go out anywhere, I didn't want to do any of that stuff. I was totally incontinent. I had no control. None at all. And life wasn't working for me. I was angry. I was upset. I didn't have any confidence that I was going to be fixed” (33).
Privacy	
2.1.7 Very private	“It's pretty private. [If you] were to interview my wife, she would [have] little to no idea of what I went through or how much [incontinence] annoyed me when things didn't work” (15).
2.1.8 Shared with family	When asked about who he discussed his incontinence with: “No. Just my wife. She's the only one who knows I went through the whole thing. It's probably not anything I want to discuss with family or friends. I pretty much kept everything a secret” (34).
2.1.9 Support group	“I did go to this support group at XXX... a few meetings ago, one of the guys talked at length about how he's doing the incontinence issue...I'm more advanced [compared to him]. What he was saying was stuff I already knew, but he was really saying it to help the new guys. [His comments] would have helped right after surgery” (30).
2.2 Incontinence mitigation or “work arounds”	
2.2.1 Condom catheter	“Yeah, it was a strange impact on my life in that I sort of sensed that this was the new reality and that there would be adapting to it. So the adaptation was primarily condom catheters or things that work in that way” (15).
2.2.2 Exercise	“The biggest thing I didn't like about the incontinency was I smelled myself, and I didn't like that. Then we changed our whole lifestyle because I retired to do a lot of things and I couldn't hardly play golf. I finally quit playing golf because I had to change diapers two or three times playing golf. I didn't like go somewhere where I had to leave somebody a diaper in their waste basket. It was just changing my life too much and I just couldn't stand it” (1). “I noticed it if I was jogging, or running, or skiing, or some athletic activity it would—there would be more urine in the pads and so forth... Not the worst thing in the world, but slightly annoying” (23).
2.2.3 Mitigation working	“I definitely would have considered [surgeries] yeah. Probably especially if it would have got worse or anything I probably wouldn't have had much choice to go on to something else” (26).
2.2.4 Acceptance of “new normal”	“You know, other than sex [SUI] hasn't [impacted me]. Because I've learned to just take it in stride” (30).
2.3 Breaking point	
2.3.1 Cumulative	“That was about a period of about 8–9 months that this was going on and my urologist, I finally told him. I said ‘I can't live this way. I need to do something’...I thought there is got to be something, that we got to do something, I can't live like this” (1).
2.3.2 Acute event (medical)	“Well, when I had the radical...I had to relearn how to use [my sphincter], I suppose. As I recall. And then I got in a motorcycle accident and [I was] catheterized and evidently it did some

(Continues)

TABLE 2 (Continued)

Patient lived experience theme	Selected quote or excerpt
2.3.3 Acute event (social)	<p>damage. After I was released I was [totally] incontinent. I was wearing diapers and I was wearing the bag and it was miserable.” (9).</p> <p>“Oh yeah, I was leaking a little bit at the time but it was not nothing drastic. It was just there once in a while I'd leak. And then I had a really bad one. I was celebrating my birthday across the street [from my old house] and was having a few drinks and I was walking across the house and I crossed the street, before I crossed the street I urinated all over myself. That was my first embarrassment with incontinence. I said wow. I was walking home by myself. Nobody knew about it but me and my wife. I said wow I cannot control this no more” (6).</p>
2.3.4 Stalled improvement	<p>“They told me that since I am improving, [I didn't need anything else]...A few months after that, I really hit a plateau. Things were—occasionally that feeling would happen, and I'd retain a little bit, but it wasn't really improving. I thought ‘This is really ridiculous. I can't live like this.’ You know, my optimism was disappearing rapidly” (29).</p> <p>“It was occasional, and then it started to be more frequent and it started to be heavier. So what drove me there was ‘Is this going to get worse? Is this something more drastic?’” (6)</p>
2.4 Finding treatment	
2.4.1 Focus on cancer	<p>“And I was going to [primary urologist] and he messed me up for a whole year and did not do a damn thing. But sent me to have MRI's and gave me pills to take to try and stop my incontinence but nothing worked. He wanted me to take another survey and take another MRI and I told him no, no, no I got to go see a doctor that's going to take care of this”(6).</p>
2.4.2 Unwilling to refer	<p>“[My Urologist] never gave me one bit of help to be able to go outside...in the meantime. So I studied myself, I am a retired professor. I got some leg bags, but then eventually the leg bags, well the item that went over the penis, would sometimes irritate the penis and so that became kind of, at times, impossible to do. Putting on several pants a day wasn't very desirable either. So then I asked a neighbor here, who is a urologist himself, and he recommended the artificial urinary sphincter” (4)</p>
2.4.3 Promised improvement that never came	<p>“They said that first, this gets better over time and it doesn't do it in a linear fashion and it sort of jumps. Let's see where we are in about 6 months or a year. It was like that for nearly 2 years. So during that time I had what—I don't know what you guys call severe—but I had effectively no storage capacity. If I stood up, whatever was in my bladder would be in whatever I was wearing” (15).</p>
2.4.3 Pads as solution	<p>“Of course I was in diapers and my doctor told me this is the way it's going to be and there wasn't much we could do. After a period of about 8 months, I think I was very depressed...I can't live like this. That was about a period of about 8–9 months that this was going on and my urologist, I finally told him. I said ‘I can't live this way. I need to do something.’” (8).</p>
2.4.4 Provider unaware of treatment options	<p>“It's funny that more doctors don't know about this procedure because incontinence is so common. I don't know how you teach them, but I guess make sure that the urologists know that this is an option other than pads or depends” (34). Incontinent for <6 months and chose AUS</p>
2.4.5 Better than other patients	<p>“You are in pretty good shape compared to a lot of people; unless you want more surgery” (5). Lived with SUI for 5 years before choosing sling</p>
2.4.6 Treatment options sooner	<p>“If anyone would ask me what I would do again with this incontinence thing, I would probably say I would have done it sooner. The main thing that I would have done sooner is I would have been a little more proactive with my urologist other than just listen to the way it's going to be. And I don't know how you do that without being called an ass, but when I told my urologist I am going to get a second opinion because I can't live like this, that's when he stepped forward and made the decision to help me.” (1)—Incontinent for almost 13 years before consultation and chose AUS.</p> <p>“And I even had gone back to the surgeon that had done the procedure, which was not at XXX, but [AUS] was never mentioned as an option. Everything was ‘Keep working on the exercises, the exercises, the exercises.’ And I didn't know this was an option. When I found out about it, I was a little disappointed that I didn't know about this earlier.” (32)—Incontinent for 3 years before consultation and chose Sling</p>

TABLE 2 (Continued)

Patient lived experience theme	Selected quote or excerpt
	“The hopes were that it would correct itself I’m sure. I’m absolutely positive that their hopes were that it would correct itself. I’ve known people who were incontinent, and it did indeed correct itself by doing Kegel exercises. That wasn’t the case with me. And everything is a delay” (33)— Incontinent for ~3 months before consultation; chose a sling after ~2 years

Note: For select quotes, clinical data of time living with SUI and choice of treatment is included for context.

Abbreviations: QoL, quality of life; SUI, stress urinary incontinence.

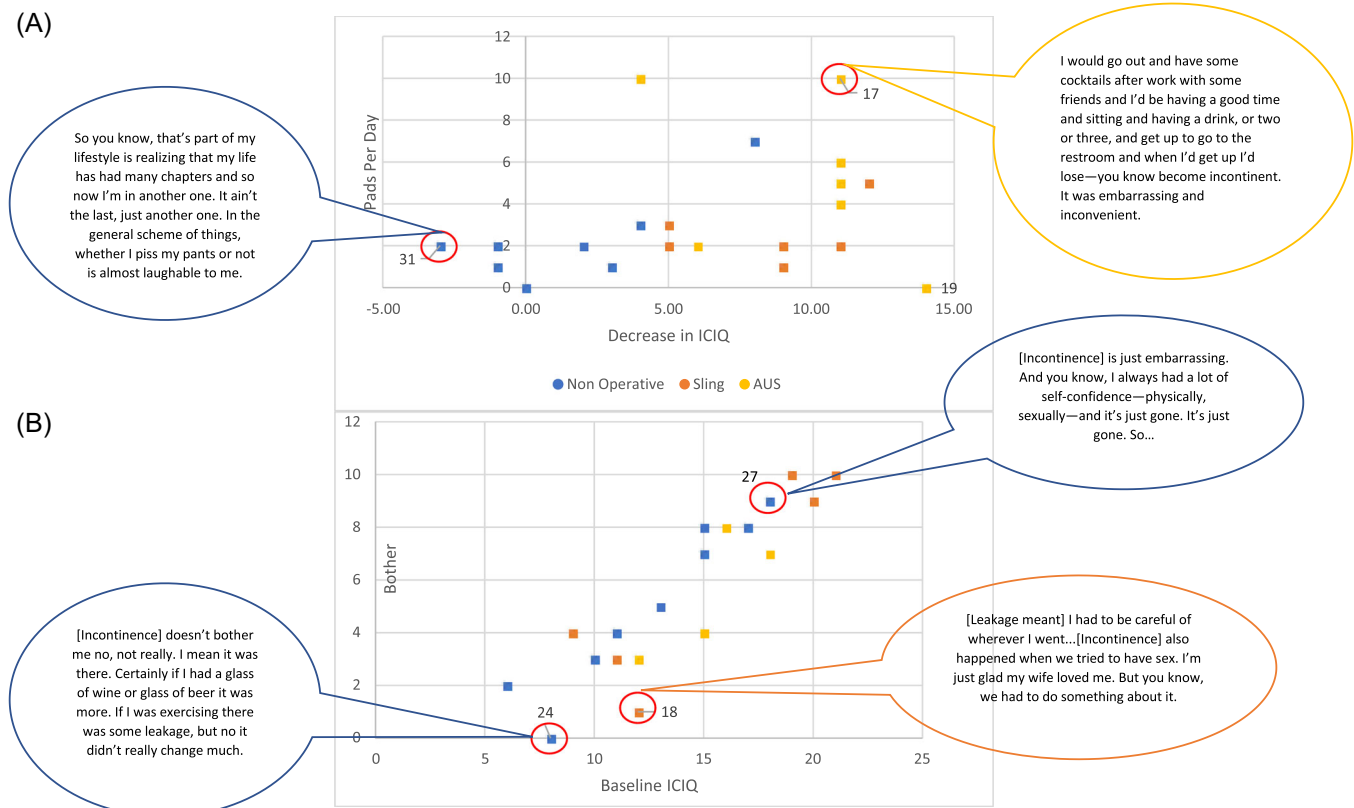


FIGURE 1 Perioperative changes (A) and baseline (B) incontinence scores, pad use, and bother. (A) Change (decrease) in ICIQ from time of initial evaluation to follow evaluation and pads per day at the time of initial evaluation. Selected quotes from labeled participants. (B) Baseline ICIQ and patient bother at the time of consultation. Selected quotes from labeled participants.

treatment during this time. For example, participant 26 had about 18 years between SUI and consultation—ultimately choosing no intervention reserving surgery for “if it would have got worse” (26) (Table 2.2.3). Similarly, participant 30, who had been living with incontinence for over 5 years, had accepted his “new normal”: “I’ve learned to just take [SUI] in stride” (30) (Table 2.2.4).

For other men this new normal is short due to degree of bother, availability of alternatives, or accessibility of treatment. Despite him noting a limited impact—“[SUI is] not the worst thing in the world, but slightly annoying” (23), he was evaluated within a year and underwent sling surgery. Similarly, Participant 33, who underwent

evaluation just 97 days after onset of SUI, noted: “I didn’t want to do any of that stuff [pads, Kegels]. I was totally incontinent...I was angry. I was upset” (33).

3.3 | Breaking point

While the time-period and degree of bother varied, men noted a clear point where they could no longer live with their incontinence. For some men this was a gestalt of missed life events due to the extremes of their incontinence work arounds while for others there was a clear inciting event that was so life-altering they could

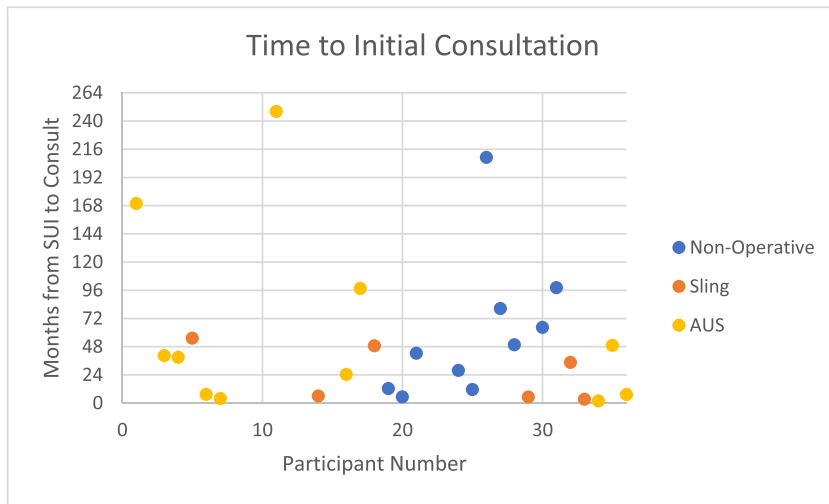


FIGURE 2 Time (days) from onset of stress urinary incontinence (SUI) to initial consultation. AUS, artificial urinary sphincter.

not continue the current course. For Participant 9 it was an acute event: “I got in a motorcycle accident and [I was] catheterized and evidently it did some damage...it was miserable.” (9) (Table 2.3.2). For Participant 6 it was a similarly acute but the incident was social rather than medical: “I was celebrating my birthday across the street [from my old house] and...before I crossed the street I urinated all over myself” (6) (Table 2.3.3). Others noted a more insidious worsening of incontinence or lack of improvement with conservative measures (e.g., Kegels) as motivation to eventually seek treatment: “I really hit a plateau...I thought ‘This is really ridiculous. I can’t live like this.’ You know, my optimism was disappearing rapidly” (29) (Table 2.3.4).

3.4 | Past the breaking point—navigating treatment

While the length of time men live with their incontinence is highly variable, once men passed their breaking point, they sought alternative options for their incontinence. Participants pushed existing providers for solutions or sought alternative providers: “I told him no, no, no I got to go see a doctor that’s going to take care of this” (6) (Table 2.4.1). Others felt dismissed by their treating urologist or were promised an improvement that never came: “[My Urologist] never gave me one bit of help to be able to go outside” (4) (Table 2.4.2–3). Participants cited experiences where pads were treated as the only solution or even when they expressed frustration with pads, they struggled to find urologists aware of treatment options: “It’s funny that more doctors don’t know about this procedure because incontinence is so common. I don’t know how you teach them (34)” (Table 2.4.4). Another participant (5) was told by his

urologist that he should contextualize his symptoms because “You are in pretty good shape compared to a lot of people; unless you want more surgery” (5) (Table 2.4.5).

Among our cohort, who by definition all reached the point of getting to SUI consultation, the unanimous and unprompted message for providers—provide treatment options sooner (Table 2.4.6).

4 | DISCUSSION

In this novel study of men living with SUI, there were clinically significant detriments to QoL and identifiable impactful windows for possible clinician intervention. Of particular importance were the findings among men who have previously been under or not studied—those who did not elect to undergo surgical treatment for SUI. While the initial decline in QoL due to SUI varies, our mixed methods data presented reinforce the existing literature on the QoL impact on men experiencing SUI.¹⁶ Men cited a negative impact of SUI on nearly every facet of daily life including work, exercise, travel, socializing, and intimacy. This aligns with prior literature which suggest worsening mental and physical function among patients with SUI.^{17–19} Indeed, the data presented in this analysis are limited to patients who sought evaluation for SUI and were healthy enough to be considered surgical candidates. Perhaps more concerning are the patients living with SUI who have suffered the described increased risks of falls, hospitalizations, and even death.^{20–25} There is likely a subset of men who are bothered but have yet to seek evaluation, some of whom—for a variety of likely predictable reasons—lost their window of opportunity to intervene on SUI.

One of the branch points for men living with SUI is the severity of the incontinence. This encompasses not only objective measures of severity (e.g., pads per day)

but also an individual's tolerance for leakage. Data suggest a significant QoL decline even at one pad per day.²⁶ This subjective nature of severity is likely why men had different breaking points, tolerance for work arounds, and ultimately chose treatment choices aligned with perceived severity. It may therefore benefit patients who are experiencing “mild” leakage to still receive counseling on treatment options. This is particularly important among the cohort of men that may require radiation who may still be sling candidates.²⁷

In our cohort, one-third of men kept their incontinence private even from their spouse/intimate partner—if these men are not asked about SUI they will likely not volunteer the information. Data suggest that less than half of men with SUI have talked with any physician about it, and that older individuals are less likely than to discuss incontinence.²⁸ Importantly, among men with incontinence who do not report it to a healthcare provider, 75% still desire evaluation and treatment.²⁹ This was demonstrated in our cohort; all but one of the men who kept SUI very private elected for surgical treatment.

There was a strong message from patients that they wished they had heard options sooner (Table 2.3.11). Furthermore, there was a substantial proportion of participants who felt that SUI was not appropriately discussed and/or managed by the urologist who previously cared for them. While the reason for frustration with a treating urologist is multifactorial, this may be a crucial time point to consider intervention. Patients and providers may feel that SUI is a “failure” and may delay treatment in hope for spontaneous resolution even beyond data supported timepoints. Men typically see their treating urologist in the “workaround” phase—this is the crucial time for referral to discuss options for SUI intervention. Our cohort highlighted this issue of access, whether it be because providers are not aware of treatment options, use their own—rather than patients’—measures of who should/should not get intervention, or people live in an area where people don’t have expertise to treat SUI. Issues of access are always more concerning in light of how effective the treatments can be.³⁰ There may also be an issue of differing timeframes for providers and patients; a physician may reasonably suggest a period of months to reassess symptom improvement which a patient may find as an unacceptable period of inaction. Appreciation for the individual patient goals is important in assessing tolerance for trial periods of various measures.

4.1 | Limitations

This study has limitations. Qualitative interviews were purposefully performed after treatment decisions had been made, given that we wanted to gather information

about the entirety of the SUI experience in retrospect. Therefore, there may be some recall bias regarding symptoms before treatment amongst those men who underwent treatment. However, we believe these data are important given that the goal is not to comment on the efficacy of treatment options, but on the lived experience of these individuals. Similarly, patients who underwent repeat surgical intervention for SUI and experienced complications were included. We feel this allows for an accurate cross section of a cohort of men seeking treatment for SUI. With a focus on how men experienced their symptoms before any intervention, the impact is likely minimal. Men in our cohort who did not receive surgical intervention after evaluation were confirmed to have not undergone surgical intervention with another practice in the study period. Lastly, this study is not meant to examine the decline in pad use following intervention or similar clinical outcomes previously described in larger series designed to offer these insights, rather objective data is included to highlight the variability in patient response to similar clinical situations.

5 | CONCLUSION

Patients who experience incontinence following prostate cancer treatment experience and seek treatment follow a predictable pattern: they adjust to SUI, attempt to mitigate how this affects their lives, and ultimately hit a breaking point—due to worsening symptoms, a particularly extreme event, or cumulative frustration. This lived experience then culminates in the desire for change. Whether that desire to change leads to treatment is variable. Of great concern to providers and patients alike are the barriers that patients experience to gaining access to SUI evaluation and treatment. Early intervention and outreach are likely to be of great benefit to this population and are currently missing.

AUTHOR CONTRIBUTIONS

Nathan M. Shaw: Data analysis and manuscript drafting. **Benjamin N. Breyer:** Critical revision and supervision. **Louise C. Walter:** Conception and design, critical revision, funding, and supervision. **Rebecca L. Suddore:** Conception and design, critical revision, funding, and supervision. **Anne M. Suskind:** Critical revision, funding, and supervision. **Caitlin Baussan:** Data acquisition and administrative/technical/material support. **Kathryn Quanstrom:** Data acquisition and administrative/technical/material support. **Isabel E. Allen:** Data analysis and statistical analysis. **Matthew R. Cooperberg:** Critical revision, funding, and supervision.

Dan Dohan: Critical revision, data analysis, statistical analysis, and supervision. **Lindsay A. Hampson:** Conception and design, data acquisition, data analysis, statistical analysis, critical revision, funding, and supervision.

ACKNOWLEDGMENTS

This work was supported by National Institute on Aging GEMSSTAR 1R03AG064372-01 (PI: Hampson), National Institute on Aging K24AG054415 (PI: Sudore), NIH/NIDDK K12K083021 (funding: Hampson), Doris Duke Charitable Foundation CTSI-UL1 TR001872 (PI: Hampson), Claude D. Pepper Older Americans Independence Center UCSF Research Education Component Scholar Award (PI: Hampson), and San Francisco Veterans Affairs Medical Center (Hampson, Cooperberg, Sudore, Walter).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Ethical approval was granted by the Institutional Review Board at the University of California, San Francisco (REF#s: 17-23374 and 19-28455). In accordance with Institutional Review Board at the University of California, San Francisco, each participant provided written consent for research participation.

ORCID

Nathan M. Shaw  <http://orcid.org/0000-0002-5710-9299>

Anne M. Suskind  <http://orcid.org/0000-0002-8437-3861>

Lindsay A. Hampson  <http://orcid.org/0000-0002-0740-7984>

REFERENCES

- Novara G, Ficarra V, D'elia C, et al. Evaluating urinary continence and preoperative predictors of urinary continence after robot assisted laparoscopic radical prostatectomy. *J Urol*. 2010;184:1028-1033. doi:10.1016/J.JURO.2010.04.069
- Resnick MJ, Koyama T, Fan K-H, et al. Long-term functional outcomes after treatment for localized prostate cancer. *N Engl J Med*. 2013;368:436-445. doi:10.1056/NEJMoa1209978
- Stanford JL, Feng Z, Hamilton AS, et al. Urinary and sexual function after radical prostatectomy for clinically localized prostate cancer: the Prostate Cancer Outcomes Study. *JAMA*. 2000;283:354-360. doi:10.1001/jama.283.3.354
- Sanda MG, Dunn RL, Michalski J, et al. Quality of life and satisfaction with outcome among prostate-cancer survivors. *N Engl J Med*. 2008;358:1250-1261. doi:10.1056/NEJMoa074311
- Ervandian M, Høyer M, Petersen SE, et al. Late urinary morbidity and quality of life after radical prostatectomy and salvage radiotherapy for prostate cancer. *Scandinavian J Urol*. 2017;51:457-463. doi:10.1080/21681805.2017.1354314
- Herr HW. Quality of life of incontinent men after radical prostatectomy. *J Urol*. 1994;151:652-654. doi:10.1016/S0022-5347(17)35038-3
- Bauer RM, Gozzi C, Hübner W, et al. Contemporary management of postprostatectomy incontinence. *Eur Urol*. 2011;59:985-996. doi:10.1016/J.EURURO.2011.03.020
- Nelson M, Dornbier R, Kirshenbaum E, et al. Use of surgery for post-prostatectomy incontinence. *J Urol*. 2020;203:786-791. doi:10.1097/JU.0000000000000618
- Gupta S, Ding L, Granieri M, Le N-B, Peterson AC. Utilization of surgical procedures and racial disparity in the treatment of urinary incontinence after prostatectomy. *Neurourology*. 2016;35:733-737. doi:10.1002/nau.22790
- Kumar A, Litt ER, Ballert KN, Nitti VW. Artificial urinary sphincter versus male sling for post-prostatectomy incontinence—what do patients choose? *J Urol*. 2009;181:1231-1235. doi:10.1016/J.JURO.2008.11.022
- Gozzi C, Becker AJ, Bauer R, Bastian PJ. Early results of transobturator sling suspension for male urinary incontinence following radical prostatectomy. *Eur Urol*. 2008;54(4):960-961.
- Hampson LA, Suskind AM, Breyer BN, et al. Predictors of regret among older men after stress urinary incontinence treatment decisions. *J Urol*. 2022;207:885-892. doi:10.1097/JU.0000000000002352
- Hampson LA, Suskind AM, Breyer BN, et al. Understanding the health characteristics and treatment choices of older men with stress urinary incontinence. *Urology*. 2021;154:281-287. doi:10.1016/j.urology.2021.05.002
- Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res*. 2007;42:1758-1772. doi:10.1111/J.1475-6773.2006.00684.X
- Michel J, Ballon J, Connor SE, et al. Improving shared decision making in Latino men with prostate cancer: a thematic analysis. *MDM Policy Practice*. 2021;6:23814683211014180. doi:10.1177/23814683211014180
- Coyne KS, Zhou Z, Thompson C, Versi E. The impact on health-related quality of life of stress, urge and mixed urinary incontinence. *BJU Int*. 2003;92:731-735. doi:10.1046/J.1464-410X.2003.04463.X
- Teunissen D, Van Den Bosch W, Van Weel C, Lagro-Janssen T. It can always happen”: the impact of urinary incontinence on elderly men and women. *Scand J Prim Health Care*. 2006;24:166-173. doi:10.1080/02813430600739371
- Kwong PW, Cumming RG, Chan L, et al. Urinary incontinence and quality of life among older community-dwelling Australian men: the CHAMP study. *Age Ageing*. 2010;39:349-354. doi:10.1093/ageing/afq025
- de Vries HF, Northington GM, Bogner HR. Urinary incontinence (UI) and new psychological distress among community dwelling older adults. *Arch Gerontol Geriatr*. 2012;55:49-54. doi:10.1016/J.ARCHGER.2011.04.012

20. Santini S, Andersson G, Lamura G. Impact of incontinence on the quality of life of caregivers of older persons with incontinence: a qualitative study in four European countries. *Arch Gerontol Geriatr*. 2016;63:92-101. doi:10.1016/J.ARCHGER.2015.10.013
21. Gotoh M, Matsukawa Y, Yoshikawa Y, Funahashi Y, Kato M, Hattori R. Impact of urinary incontinence on the psychological burden of family caregivers. *NeuroUrol Urodyn*. 2009;28:492-496. doi:10.1002/NAU.20675
22. Durrant J. Urinary incontinence in nursing homes for older people. *Age Ageing*. 2003;32:12-18. doi:10.1093/AGEING/32.1.12
23. Dobbs D, Meng H, Hyer K, Volicer L. The influence of hospice use on nursing home and hospital use in assisted living among dual-eligible enrollees. *J Am Med Dir Assoc*. 2012;13(189):189. doi:10.1016/J.JAMDA.2011.06.001
24. Morrison A, Levy R. Fraction of nursing home admissions attributable to urinary incontinence. *Value Health*. 2006;9:272-274. doi:10.1111/J.1524-4733.2006.00109.X
25. Friedman SM, Steinwachs DM, Rathouz PJ, Burton LC, Mukamel DB. Characteristics predicting nursing home admission in the program of all-inclusive care for elderly people. *Gerontologist*. 2005;45:157-166. doi:10.1093/GERONT/45.2.157
26. Cooperberg MR, Master VA, Carroll PR. Health related quality of life significance of single pad urinary incontinence following radical prostatectomy. *J Urol*. 2003;170:512-515.
27. American Urological Association. Incontinence after prostate treatment: AUA/SUFU guideline. 2019. Accessed August 14, 2022. <https://www.auanet.org/guidelines/guidelines/incontinence-after-prostate-treatment>
28. Burgio KL, Ives DG, Locher JL, Arena VC, Kuller LH. Treatment seeking for urinary incontinence in older adults. *J Am Geriatr Soc*. 1994;42:208-212. doi:10.1111/j.1532-5415.1994.tb04954.x
29. Smoger SH, Felice TL, Kloecker GH. Urinary incontinence among male veterans receiving care in primary care clinics. *Ann Intern Med*. 2000;132:547-551. doi:10.7326/0003-4819-132-7-200004040-00006
30. Wingate JT, Erickson BA, Murphy G, Smith TG, Breyer BN, Voelzke BB. Multicenter analysis of patient reported outcomes following artificial urinary sphincter placement for male stress urinary incontinence. *J Urol*. 2018;199:785-790. doi:10.1016/J.JURO.2017.09.089

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Shaw NM, Breyer BN, Walter LC, et al. How older men live with stress urinary incontinence: patient experience and navigation to treatment. *NeuroUrol Urodyn*. 2024;43:11-21. doi:10.1002/nau.25325