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Patient-Identified Treatment Attributes among Older Men with Stress Urinary Incontinence: A Qualitative Look at What Matters to Patients Making Treatment Decisions

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Abstract

Objective: To investigate which treatment attributes matter to patients with stress urinary incontinence (SUI), why and how they matter, and the context in which patients consider treatment attributes. Nearly a quarter of older men have decisional regret following SUI treatment. Knowledge of what matters to patients when making SUI treatment decisions is necessary to improve goal-concordant care.

Methods: We conducted semi-structured interviews with 36 men 65 years of age with SUI. Semi-structured interviews were conducted by telephone and transcribed. Four researchers (LH,

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NS, EA, CB) coded the transcripts using both deductive and inductive codes to identify and describe treatment attributes.

Results: We identified 5 patient-derived treatment attributes of interest among older men with SUI who have faced treatment decisions: 1) dryness, 2) simplicity, 3) potential need for future intervention, 4) treatment regret/satisfaction, and 5) surgical avoidance. These themes reliably emerged in our patient-centered interviews from within various contexts, including prior negative healthcare experiences, the impact of incontinence on daily and quality of life, and the mental health burden of incontinence, among others.

Conclusion: Men with SUI weigh a variety of treatment attributes in addition to dryness, a traditional clinical endpoint, and do so within the context of their individual experience. These additional attributes, such as simplicity, may run counter to the goal of dryness. This suggests that traditional clinical endpoints alone are not adequate for counseling patients. Contextualized patient-identified treatment attributes should be used to create decision support materials to promote goal-concordant SUI treatment.

Keywords

male stress incontinence;	decision-making;	aging;	qualitative	

Background

About 25–30% of men will have stress urinary incontinence (SUI) at 1 year following prostatectomy, when improvements are known to plateau, yet only 3–6% of post-prostatectomy men undergo surgical SUI treatment. Thus, many older men are living with untreated incontinence, resulting in poorer quality of life (QOL), embarrassment, shame, social isolation, and depression. Data suggest that some older men regret their decision to forego SUI treatment; one-fifth of men with SUI have moderate to severe decisional regret around SUI treatment after treatment decisions, and the overall rates of decisional regret are significantly higher for those electing conservative management compared to surgery (35% vs. 8%, p = 0.001). Thus, prostate cancer survivors with SUI are not necessarily making goal-concordant choices about SUI treatment.

One reason for this discrepancy could be that SUI treatment decisions are complex, particularly for older men with multiple competing health and lifestyle considerations. Seventy percent of operations for male SUI are performed in men aged 70 or older, and data show that multimorbidity, functional impairments, and limited life expectancy are common in this population. In addition, SUI treatment decisions are made within the context of prior treatment and surgery experiences – sometimes surgeries which, in fact, resulted in the incontinence in the first place. Adding to the complexity of these treatment decisions, treatment options for male SUI vary significantly in terms of risks, benefits, and leakage-related outcomes. In this light, patients must weigh not only multifaceted risks and benefits of treatment options within their individual contexts, but also how treatment fits with their own prognosis, values and goals. Decision support for patients with SUI is needed to improve receipt of goal-concordant care for SUI among older men.

Physicians counseling patients regarding treatment options may incorrectly assume they know what patients' primary goals or values are. Surgeons may reasonably assume that the primary preference of the patient is to be completely dry, while for patients this decision may be more complex. Patients must weigh their desire for dryness with the other treatment aspects, such as the desire to avoid a mechanical device or having to potentially undergo another surgery in the future. This is further complicated by highly variable patient bother at similar levels of SUI; some patients report tremendous bother even at 1 pad per day. ¹² Thus, to promote goal-concordant care for SUI, we sought to identify through semi-structured interviews which elements of treatment matter to older patients making SUI treatment decisions.

Methods

We conducted semi-structured interviews between 5/2017 – 5/2018 with men who had undergone consultation for treatment of SUI at the University of California, San Francisco Medical Center and the San Francisco Veterans Affairs Medical Center. These men were recruited from a larger quantitative study and were asked at the completion of their participation with the quantitative survey if they would be willing to participate in a qualitative interview. We set out to interview at least 10 individuals from each treatment group (artificial urinary sphincter, sling, and no surgery) after patients had made treatment decisions/undergone surgery.

Interviews were conducted by telephone by trained study personnel (LH, CB, KQ) using an open-ended guide that was developed pilot tested, and refined by the principal investigator (LH) and a qualitative research expert (CC, identified in acknowledgements). (Supplement 1). The interview guide focused on the following main content areas: 1) diagnosis of SUI, 2) treatment options, 3) treatment decision, 4) surgical expectations, 5) surgical outcomes. Interviews were approximately 30 minutes (range 16 minutes – 76 minutes) and were audio recorded for transcription. Participants were provided a \$20 Amazon gift certificate after completion of the interview.

Two members of the research team (LH, CB) reviewed transcripts after the first five interviews and thereafter on a regular basis throughout the interview process to identify initial themes and assess for thematic saturation. Through this process the interview guide was reviewed and further refined to include additional foci of interest that arose within interviews and were felt to be important. Recruitment was paused when content saturation was felt to be achieved. Institutional review board approval for the study was obtained at the University of California, San Francisco (IRB No. 17–23374).

Four researchers (LH, NS, EA, CB) then reviewed and coded the 36 transcripts using Dedoose (Los Angeles, CA: SocioCultural Research Consultants, LLC). ^{13–16} The initial coding scheme was derived from a first pass of all available transcripts by all coders. After identification of themes, NS and LH re-coded the transcripts, comparing, discussing, and agreeing on each code throughout the transcripts. Codes were subsequently grouped to develop themes and subthemes, using a combination of deductive and inductively-identified codes that captured treatment attributes valued by men with SUI. Emergence of new themes

or trends prompted a review of all transcripts for the same. By the time all 36 interviews had been coded and recoded, all agreed that no new themes were emerging and that themes were well-saturated. After complete review, a final expert (DD) was consulted to guide organization of themes.

Results

Participants:

36 men were interviewed, with a mean age of 74 (range 57–88). All but one had developed incontinence as a result of treatment for prostate cancer. Five of the men reported preevaluation leakage of only one pad per day, 20 used two or more pads per day, and 11 used incontinence briefs. Of the participants, 14 underwent sphincter, 12 underwent sling, and 10 elected no surgery.

Treatment attributes:

We identified five patient-derived treatment attributes of interest among older men who have faced SUI treatment decisions. Table 1 shows illustrative quotes; when possible, we also include a key phrase in the results text.

Dryness.—A treatment attribute that was important to all participants was understanding the likelihood of dryness of any particular treatment option. For many, this was a key treatment attribute, but how much they valued this attribute varied by individual. While some expressed the primary importance of being completely dry ("tossing away the pads" Participant 14), others voiced a goal to decrease the amount of leakage ("any improvement" Participant 11). The theme of dryness arose within multiple contexts. First, the theme of dryness was important in the context of impact on one's daily life/quality of life, as Participant 22 noted when talking about the most important aspect of his decision-making ("being able to logistically be more free"). Second, dryness was also thought about in the context of the mental health burden of incontinence ("I got so depressed" Participant 7). Finally, dryness was valued in the context of one's own individual health – well summarized by Participant 29, who was particularly articulate in forecasted a time when he might not be able to operate a sphincter device but still desired some improvement in incontinence ("And so at least a backup, at least the sling, there will be something; it won't just be running out every time you stand up").

Simplicity.—Many valued the simplicity of the treatment choices presented when making decisions. In some people's minds, simplicity played into their decision process in terms of starting with the "easiest", "simplest", or "least invasive" option and moving up from there as needed. In some cases, this meant that people wanted to undergo what they saw as a simpler treatment option first, knowing that a future, more aggressive treatment was available if the first failed ("do the sling first" Participant 29).

For some simplicity meant avoiding having a mechanical device in one's body, such as for Participant 25 ("it's just so mechanical and inside my body"). For others, the importance on simplicity mostly revolved around minimizing risks and complications which are higher

with an sphincter, such as for Participant 15 ("my sense was that the sling was pretty innocuous and the sphincters are pretty obviously harmful").

Need for future intervention: For many, the potential need for future intervention played a role in determining which treatment option they chose, if any. In particular, this theme arose in the context of minimizing risks and complications such as future repeat surgery related to the sphincter erosion, infection, or malfunction requiring removal and replacement of the sphincter ("it could be three years before you have to change out, it could be five, it could be six months" Participant 29). Similarly, men noted a desire for a single surgical fix and avoiding repeat surgeries. This was a main reason Participant 20 did not opt for sphincter ("what *the surgeon+ suggested wasn't a single surgery"). In addition, a few participants considered their own health when weighing the need for re-treatment ("I was really concerned about my age" Participant 29).

Treatment regret/satisfaction.—Several participants noted that it was helpful to understand others' experiences with treatment ("it would have been good to hear other people's experiences" Participant 13), and contextually this was often linked with treatment expectations. In particular, there was a notion of understanding others' experiences in the context of treatment satisfaction/regret. Participant 15, for example, valued knowing whether people regretted their decision afterwards ("Am I going to wish that I hadn't done this?") over weighing risks and benefits.

Surgical avoidance.—Some participants expressed strong desires for surgical avoidance ("I would not be open to surgery under any circumstances" Participant 31) and many with these feelings did not undergo surgery. However, for some, the quality-of-life impacts of the incontinence were great enough that despite their reservations they ultimately pursued surgical treatment.

One underlying context which was important to surgical avoidance was individuals' previous negative healthcare or surgical experiences. Given that most of the men with incontinence had undergone prostatectomy, these were sometimes – but not always – related to their prostate cancer treatment. Trauma colored the perspectives of several, such as Participant 27 ("I was still so traumatized [after my prostate surgery]"). Others had undergone numerous surgeries which greatly affected their perspectives ("I wasn't too keen on more surgeries" Participant 24).

Another reason for surgical avoidance was the concern for difficult surgical recovery within the context of their overall health, comorbidities, or age. For example, Participant 20 noted ("as you get older, it's harder to overcome those things"). Similarly, Participant 29, noted the potential impact of anesthesia on cognitive function ("it's not good for your memory and dementia"). Finally, Participant 31 noted how his life expectancy shaped his desire to not spend any more time in the hospital than he needed to ("I mean, every day is a gift. So, you know, would I choose to spend a gift in the hospital? No.").

Discussion

In this qualitative study of older men with stress urinary incontinence, we found that patients care about several aspects of treatment, not solely on dryness during treatment decision-making. Patients bring to bear their past experiences, preferences and the QOL impacts of their incontinence when making complex treatment decisions. While dryness is a major factor, our data show that men also consider simplicity of treatment options, potential need for future re-treatment, treatment satisfaction, and surgical avoidance. These themes arise in the context of individuals' own life experiences and particular circumstances. Contextual factors which influenced them included personal previous negative healthcare experiences, treatment expectations, individuals' quality of life and mental health burden related to their incontinence, individuals' perception of their own health and prognosis, as well individuals' desire to minimize risks and complications, avoid mechanical devices, and avoid repeated treatment. These findings show how important it is for older men, along with their providers, to make well-informed individualized treatment decisions to maximize patient-centered care and outcomes.

Our thematic analysis underscores the point that traditional clinical endpoints are not necessarily adequate for counseling patients who face complex socio-medical decisions. Studies show that the outcomes that clinicians value, including those they may assume patients' value, may not actually be shared by patients. For example, researchers found that patients were willing to incur increased risk of perioperative mortality and amputation in order to receive vascular surgery locally rather than having to travel long distances for treatment. ¹⁷ Data such as these show us that patients may prioritize factors differently from treating providers, and it is crucial to identify and address these disparate priorities.

Clinicians may turn to objective measures such as dryness when making treatment recommendations because they are studied and measurable outcomes while other attributes may be harder to define, measure and quantify. Hopefully this is changing; in a recent study, one group evaluated endpoints such as bother, impact, and distress of urinary incontinence in an effort to focus on patient-oriented outcomes, even identifying clinical characteristics that influenced these outcomes. ¹⁸ Through open-ended interviewing we elicited additional patient-derived treatment attributes that were important to patients in this decision-making process. The attribute of simplicity of treatment options, for example, was important to many, even among some who chose sphincter surgery. This theme often arose in the context of thinking about a mechanical device. This reinforces that while a sphincter might provide the best chance of dryness, patients may still benefit from hearing about other, "simpler" treatment options. This is in-line with a previously published study of male SUI, showing that 25% of patients who were counseled by their urologist to undergo an artificial sphincter would still choose a sling, even against the recommendation from their urologist, because of a desire to avoid a mechanical device. ¹⁹

Other patient-derived themes that arose in our analysis are important to consider in terms of patient counseling. For example, many interviewees focused on the potential need for re-treatment in the future, and this played a large role in their treatment choice; counseling patients about the likelihood of re-intervention in the future is thus critical in ensuring

that patients can make decisions in line with their own goals. For some, the experience and satisfaction (or dissatisfaction) of others weighed into their decision-making. Along these lines it can be helpful to provide patients with data on patient satisfaction of various treatment types, or opportunities to talk with others who have faced the same treatment decisions.

Our data showed that context and past experiences can inform patients' priorities when making treatment decisions. Many men with SUI have had negative interactions with the healthcare system, including the treatment that caused incontinence. It is not surprising that patients may be wary of seeking further treatment. Nevertheless, men who don't elect SUI surgery experience higher levels of regrets and lower quality of life. Taken together, these data speak to the need to empower, engage, and build trust with patients in order to get them to treatment (when desired) that improves their quality of life.

There are several limitations to this study, which focuses on individuals' experiences but does not encompass or represent all perspectives. There is, of course, significant biases based on the pool of patients being drawn from those who sought treatment for SUI; this likely means there are groups who are either less bothered by similar symptoms or not offered treatment options. We conducted interviews until we reached saturation with no new themes arising in interviews, thus providing reassurance that we captured the experiences of the patient population we did engage. This is the first study, to our knowledge, to examine male SUI treatment decision-making qualitatively and thus, despite these limitations, provides patient-centered perspectives on improving decision-making.

Conclusion

In moving towards goal-concordant treatment decision-making for male SUI, informed patients' voices are essential. Patients may have multiple goals and values when it comes to SUI treatment, beyond dryness, that are critical to take into account to provide individualized counseling and decision-making; providing counseling focused on treatment simplicity, future need for re-treatment, surgical avoidance, and treatment satisfaction may help to reduce decisional regret and lead to better patient-oriented care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

SUI stress urinary incontinence

QOL quality of life

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Table 1:

Participant Quotes by Attribute

ATTRIBUTE	PARTICIPANT	QUOTE
	14	Success meant not being incontinent. I mean the idea was just tossing away the pads.
	11	Being incontinent is terrible when you're wet all the time It's horrible. So, any improvement was acceptable to me.
	22	Just being able to logistically be more free just changing a pad once a dayis just much less than having to pack full packs of pads around with me and to have a plastic bag ready to throw the used ones in.
	7	I got so depressed, I wanted to commit suicide. You just couldn't do anything. In fact, I told friends that I wish I had just let the cancer catch up with me because it probably would have taken several years, but I would have had years where I lived with a normal life.
	29	I thought about 'What if there comes a time when I'm not well enough to do anything or if I have arthritis and I can no longer manage the valve down there, and it stops working then I'm going to be leaking like a sieve and anyone who has to take care of me or help me, that's going to be horrible.' And so at least a backup, at least the sling, there will be something; it won't just be running out every time you stand up.
29 25 15	29	My notion is to do the sling first.' I said 'If it doesn't really work the way I think it could work, can we do the sphincter afterwards?' He said "Yes, we could do that." so I said 'Okay, I want to do the sling.'
	25	So I'm not against the operation. I'm just worried about the mechanics of it; it's just so mechanical and inside my body.
	15	Oh, yeah. Um, my sense was that the sling was pretty innocuous and the sphincters are pretty obviously harmful. I mean I understand how they work and the urethral sphincter strikes me as something that I would never recommend to anybody. It's a plastic thing squishing a living thing and the chances that it's going to do that again and again forever and ever without the living thing dying or developing a hole, or something like that, struck me as pretty small.
Need for future intervention	29	I finally did the sling surgery, although it was really not suggested that the sling would be good for me. He felt that the artificial sphincter would be the thing. But I'm an ex-med device guy and I'd read up on the artificial sphincter and it could be three years before you have to change out, it could be five, it could be six months. It all depends It's just a bunch of tubes and a pretty simple mechanism, but I guess you still have failures anyway
	20	The principle thing in my mind was that [the surgeon] said "These things do fail. They don't—there are always situations where your body rejects them or what have you." Basically what he suggested to me wasn't a single surgery where you could implant it and be done with it.
	29	Well, my goal was not to have surgery every three years. I was really concerned about my age. I was 73 when I had my surgery, now I'm about to be 76, and soon I'll be 80 something. I know some people have been changed out a couple of times and I know that things happen, and you could have erosion and wearing through your urethra and they have to move it around to change it.
Treatment regret/ satisfaction	13	I actually wished that I had someone to talk to. Like I said, I did a lot of research online but I also wish that I had someone to talk to before I went into this. Not that I probably would have changed my mind because my mind was set, but just to hear the stories. You know? It would have been good to hear other people's experiences.
	15	It seems obvious that someone would like to know what are the chances that this surgery will fail, what are the chance that I'm going to need to get it re-done, what are the risks of infection, what are the chances that am I going to be worse off than I am today? If you list all those chances, and you put the statistics by them I don't think that informs anybody about anything. I don't think it addresses the question, 'Am I going to wish that I hadn't done this?'
Surgical avoidance	31	I would not be open to surgery under any circumstances.
	27	I was still so traumatized by the surgery of the RPI think it was just I didn't want to ever have another surgery Stress comes up when I think about any kind of surgery, and the stupid decision I made to go ahead with the RP.
	24	Just a major surgical procedure, and since I'd already been through a prostatectomy plus two inguinal hernia repairs after that, I wasn't too keen on more surgeries Well, to have more surgery, it might not work, and from my initial—my inguinal hernia repairs—I've been left with some pain and tenderness in my lower abdomen as a result of cutting the nerves, and I just didn't want to do it anymore.

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ATTRIBUTE PARTICIPANT QUOTE

20 [W]hen you're in your 70's you're not actually anxious to have surgery, you don't feel like you have the recuperative power that you had when you were younger. And I just came to the conclusion that a serious surgery has lots of recuperative stuff that I didn't have to worry about when I was younger... Everything bounced always back, it just healed up, and went on with life. And I just realized that that just doesn't happen. And as you get older, it's harder to overcome those things.

29 I have a good [doctor] friend of mine ... He avoids going under for whatever reason, because it's not good for your memory and dementia. He said, 'Every time you go under, you stand a chance coming out not as good as you were before.' And I thought 'How many times do I want to go under and have a major surgery?' It's always impacted how I think about going under again.

31 You know, walking around with advanced stage-4 cancer for 12 years, you have to be optimistic. I mean, every day is a gift. So, you know, would I choose to spend a gift in the hospital? No.

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