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How Men Manage Bulbar Urethral Stricture by Concealing Urinary Symptoms

Abstract

In this article, we present findings from research conducted as part of a multi-center surgical trial. Bulbar urethral stricture, a narrowing of the middle urethra, is a common cause of urinary problems in men that can have a profound impact on their lives. Semi-structured interviews were conducted with a sample of 19 men seeking treatment for urethral stricture. The findings reveal how men tend to develop routines and tactics to adapt to their symptoms and hide them from others rather than seek help. We argue that this concealment becomes an inseparable part of how the disease is managed and is an additional hidden practical and emotional burden for these men. In addition, we suggest that the patients only sought curative treatments once practices of social concealment are no longer viable.

Keywords: health seeking; health experiences; illness and disease; men's health; gender; sensitive topics; symptom management

Introduction

Urethral stricture is the commonest cause of difficulty passing urine in younger and middle-aged men with a prevalence of approximately 200 per 100,000 men in their 20s, rising to 900 per 100,000 men in their 70s (Anger, Buckley, Santucci, Elliott, & Saigal, 2011; Santucci, Joyce, & Wise, 2007). A urethral stricture is a narrowing of part of the urethra that reduces or blocks the flow of urine from the bladder and mainly occurs in the bulbar urethral segment. This narrowing or blockage is due to scarring occurring after tissue damage that can have a range of causes, most commonly physical injury or infection. Affected men experience symptoms of poor urine flow, feeling of incomplete bladder emptying, pain on voiding, urine leakage, and cystitis. Typically, a stricture is treated with an endoscopic urethrotomy, which involves widening the urethra by cutting a channel through scar tissue using a knife mounted on the end of an endoscope. However, this operation tends to be associated with a high rate of stricture recurrence, requiring several repeat operations over a number of years. The alternative is specialized reconstructive urethroplasty, which involves open surgery to replace damaged tissue with a graft. Outcome measurement after treatment of urethral stricture has typically been confined to variables such as flow rate and urethral caliber; yet, there is evidence that men with urethral strictures have different perceptions of how success should be measured (Jackson et al., 2011; Kessler, Fisch, Heitz, Olianas, & Schreiter, 2002). This led to the development of a patient-reported outcome measure based on change in relevant lower urinary tract symptoms (LUTS) and health state (Jackson et al., 2011). However, patient-reported outcome measures are unable to provide meaningful accounts of the social impact of urethral stricture. While urinary symptoms do impact considerably on men's quality of life (Jackson et al., 2011), the authors are unaware of any research accounting for how this might happen. Understanding day-to-day experiences of living urinary symptoms is relevant to clinicians who may not get the opportunity to explore the effect of urethral stricture on their patients' wider activities. This study sought such insight and this article provides a unique picture of the patient experience that will also help to inform and improve urethral stricture treatment decision making.

Material and Method

This was a qualitative interview study conducted alongside the feasibility phase of a United Kingdom National Health Service (NHS) multi-center trial randomizing men seeking treatment for recurrent bulbar urethral stricture to one of two treatment groups: open urethroplasty or endoscopic urethrotomy (www.opentrial.co.uk). To be eligible for the trial, men had to require intervention for urethral stricture and were deciding between endoscopic management by urethrotomy (cutting) and reconstructive surgery by urethroplasty (a graft). Men were approached about the trial during their treatment decision making at urology sites across the United Kingdom. Regardless of whether or not they decided to participate in the trial, all the men were also asked whether they would consider discussing their decision in an interview. Those willing to be interviewed were contacted by the researcher (P.W.). At the close of the qualitative study, 25% (40/159) of those screened for trial participation had said they would be willing to be interviewed. Importantly, patients were only eligible for the trial if they had previously received a failed treatment. Therefore, all men eligible for the trial, and subsequently for the qualitative study, had undergone a least one surgical intervention for urethra stricture prior to the interview. Following research ethics approval (reference: 12/NE/0343) and individual informed consent, semi-structured interviews were conducted with men in both treatment groups, exploring their experiences of living with symptoms, with a focus on encouraging them to express priorities and preferences in stricture treatment. Men were purposively sampled from five hospital sites across England. All interviews were audio-recorded and conducted by the researcher (P.W.) either face-to-face or by telephone using a topic guide. The interviews were designed to begin with an open conversation and move onto more detail. Each interview began with a conversational invitation for the participants to tell the researcher about themselves, followed by specific questions such as “who can you talk to about urethral stricture?” and “have there been times when it has caused you embarrassment?” The men interviewed often had long illness narratives and described operations they had in the past, more recently, or were anticipating. Recordings were transcribed verbatim by a transcription company, checked, anonymized, then coded and analyzed following the principles of thematic analysis (Braun & Clarke, 2006; Rapley, 2011). Thematic analysis was adopted because it provides a flexible way of exploring the shared beliefs, narratives, and accounts of a group. It is also a helpful process for identifying emergent patterns with the data. This article draws on a small set of the themes developed from the broader analysis: those relating to “symptoms,” “concealment,” and “help-seeking.” In practical terms, we initially undertook “in vivo” and open coding, transcript by transcript, iteratively developing the codes. We reviewed the codes, searched for potential themes, and refined them and the connections between them. We used specialist software to support the management and retrieval of data (Weitzman, 1999), as well as writing analytic memos and using tables, process maps, and diagrams to further explore and refine emergent issues. Analysis was also supported by discussion in trial meetings and regular qualitative data clinic sessions, which included health professionals and social scientists from a range of clinical and academic backgrounds.

Results

Nineteen men, ranging in age from 25 to 70 years old (median = 36) were recruited from five urology clinics across England. Interviews took place between February and November 2013. The type and severity of symptoms were broad; the most common were reduced urinary flow, urgency, and an inability to empty the bladder (urinary retention). Although not always painful, the physiological sensation of a stricture was described as unnatural and associated with discomfort and frustration. The main concern for patients was the impact that these symptoms and prolonged toilet visits had on their lives.

Urgency and Retention

Men repeatedly described their frustration at having a recurrent sense of urgency while not being able to empty their bladder. They struggled to describe the physiological sensation, giving rise to notions of there being a "blockage" and of something "being wrong." Several of the men described the sensation as "burning," although for most this was "uncomfortable" or a "dull ache" rather than painful. Nonetheless, the sensation of a full bladder was upsetting and frustrating, causing significant distress. One described it as "horrible . . . it's like a torture" and another noted,

> *Imagine like all the time needing to go to the toilet and eh, not being able to basically . . . that's what it was and that was horrific.*

Periods of retention were sporadic and could last for hours. When symptoms occurred, it was necessary to stop activities and head home. Sitting in a hot bath, urethral massage, or trying to relax were common methods men used to try to empty the bladder. Participants often structured their work and life so they could carry out symptom management without others knowing. Recurrent urgency and retention caused considerable distress because of the interruption to day-to-day life. Nocturia (waking up to pass urine) was a common problem. Some participants described having not slept properly in years.

> *Before the operation, I could be waking up anything to 6 or 7 times [in four] hours to go to the toilet. Being constantly tired: It's horrible, it's so draining.*

Although nocturia was frustrating, it was at least something that could be tolerated at home and in private. Managing symptoms during the day caused a different set of problems with men expressing exasperation in trying to maintain concentration during detailed work.

> *I am doing a lot of technical work and things like, you know, I keep on going to the toilet it's really a pain. It just, yeah, especially when I am doing very intricate things in the workplace I get a bit nervous and I get urgency to go to the toilet like it's really [sighs and stops].*

Participants reported that the sense of urgency would arise unexpectedly, resulting in a constant sense of anxiety. Further analysis showed that expression of worry and anxiety associated with the threat of sudden urgency and retention was present throughout the interview data. Men were particularly concerned about social embarrassment and reported a fear of being "caught out." The fact that this was "always in the back of your mind" illustrates the wider pervasiveness of symptoms beyond their actual occurrence.

Secrecy

In general, men felt that urethral stricture was not to be discussed and should be kept secret. Because bulbar urethral stricture involves the penis and urination, it was not something men felt comfortable discussing with others or, as this man said,

> *No, no I didn't tell anybody. No, nobody could have noticed it not unless I let somebody know. It's not something you want to shout about!*

Several men described omitting details or avoiding telling even their closest family about their condition. One man described how, although his wife knew what was going on, he pretended to his friends and children that his regular hospital visits were for knee treatments.

> *It's funny you've got a little secret that you can't tell anybody. Because I can sit there and talk to people about a lot of health-related issues, but this is the one thing that I won't let anybody know about—and I wouldn't talk about.*

While desire for privacy is understandable, it can mean that these men miss out on the potential therapeutic benefits of talking about their illness to others.

> *My immediate family know that I have to have operations and things; that things aren't ideal. But there's not a great deal of discussion that goes on—just the sort of interaction about when things are happening and how things are in general. I wouldn't say there have been any specific details discussed.*

This was also evidenced by many of the patients making treatment decisions alone and reporting little support from friends or family.

> *I think if I told my family, they'll just make a fuss out of things. No, I kept it quiet. I didn't have any support from friends and family because I didn't inform anyone.*

Although they preferred to conceal their condition from others, many participants expressed an interest in learning about other men with stricture. The idea that there were other men like themselves was reassuring, and contributing to a study made many participants feel like they were giving back to such a community. One participant even said that he planned to start a support group for men with urethral stricture. Interestingly, however, he only planned to do so once his own symptoms were resolved.

Planning and Routines

To help conceal the condition and maintain the appearance of normality, patients described planning their days around toilet access. For example, one man described preceding any activity with several attempts to empty his bladder.

> *[I am] so self-conscious about it if it was the case of we're going out to go and do the food shop I would start getting ready half hour before obviously get your shoes on and do whatever you need to do but it was a case of like first thing go to the toilet then I'd go and do something and it would be go back to the toilet and go and do something else and then go back, I would go to the toilet about five times in half an hour and go out every half hour I would have to go to the toilet again.*

Another routine would be a hot shower before going out or placing tissue or cloth in the underwear to disguise urine leakage, a symptom referred to as "post-micturition dribble." Self-dilatation, which is the use of a catheter tube to temporarily stretch the urethra, was also used tactically as part of a routine. For example, another man described his long-held routine for managing his stricture involved daily self-dilatation (also termed self-catheterization).

> *Yeah, I self-catheterize in the morning and then I have a flow all day. Occasionally, I try missing out on the next morning sort of thing because I think it's got a good flow but by the evening it's almost stopped and then the next day when you catheterize it's harder to do so*

> *it's as well just to catheterize every day [slower] that way it doesn't upset anything and keeps it all going.*

Like other men, this planned self-dilatation allowed him to "just work round" and not "upset" his activities or his social appearance of normality. Self-management allowed him to continue his life without his friends or colleagues having to know about his urinary problem.

Not Drinking

Another aspect of planning and routine used to manage symptoms was restricting fluid intake. Some men said that they preferred to feel thirsty rather than risk urgency. One participant had been living with a stricture for a relatively short amount of time and said that he was starting to avoid liquids to both sleep better and keep working.

> *I am supposed to be drinking a lot of water [according to my doctor] but recently I've been pretty bad but it's only because I am absolutely sick and tired of going to the toilet at night! If I have a lot of work to do I tend to drink less so I don't have to go, you know what I mean? Rather than take me from my work. Probably it's not the best like in terms of, you know, my health 'cause my doctors tell me I have to drink loads of water but, you know, sometimes it's just not practical.*

For those who have lived with the condition for decades, tactics for managing their stricture have become second nature. One man in his 60s had lived with stricture symptoms most of his adult life and says that not drinking was something he had become accustomed to. Here he describes tactically avoiding colleagues' offer of drinks.

> *At work you're always getting offered cups of coffee or cups of tea or a drink and I used to turn them down all the time. I'd just pretend I'd had one at the premises before; the real reason was I didn't want to start keep trying to find somewhere to pee all the time and because it used to take so long and you used to get that pain build up with a full bladder. So I didn't, I really don't drink enough fluid now even because it became a habit I didn't drink a lot of fluid at all and the wife often commented "you've been all day without having a drink" but to me that's normal.*

Social Avoidance

Many interviewees were concerned about others noticing the time they spent in the toilet or at a urinal. Public toilets were particularly risky places where urinary problems might be exposed. Bars were a commonly discussed example of this kind of risk because they involved a combination of drinking and socializing. Many were concerned about being "caught out" and exposed to others, and preferred to appear unsociable.

> *There's times when I've been out and I think "Shit I can't go to piss! I can't go to the toilet! I can't do this: I've got to go!" and everyone says "What are you doing?" and I say "Oh, I'm just nipping off somewhere" and then just go home.*

Many of the participants talked about times that they had made excuses to leave social events or refrained from attending altogether.

> *I have done it . . . been to parties and things, [I] thought I was okay I'd been catheterized weeks before and then went in. It's usually when you drink some, [a]lot like if you drink a lot of alcohol or something different it can sort of you get a burning sensation or something like that which then makes it swell up, or something like that, and you just can't go—you've got*

> *to go home catheterize and you're right. But I mean you, you make excuses, go home, catheterize, [. . .] I've gone home but I've never gone back to the party. I've just made an excuse to disappear, aye, they all wanted to know where I'd gone [. . .] I mean you don't go shouting off: "I've got a stricture and I've got to go home!"*

Such accounts speak about both the effect that urinary symptoms have on these patients' social lives and also the emotional burden of concealment and secrecy. The above participant had lived with the condition all his adult life and such concealment significantly impacted on his activities, confidence, and how he felt he was perceived. Nearly every participant told a story about almost being exposed at a public toilet or social situation. These moments of anxiety and embarrassment could prompt the man to become more insular about his condition. However, this could also be the moment at which a man decides to seek help.

"Getting on With It"

Despite clearly being distressed, many men downplayed the severity of their condition, saying that it was "not life threatening." This meant that they felt they should tolerate symptoms and not "make a fuss." Such findings reflect previous research into men's health and masculinity that highlight how traditional notions of male identity, such as being tough, resilient, and independent, can undermine men's health seeking and acknowledgment of problems (Courtenay, 2000). One method of downplaying the condition was to compare urethral stricture with more severe disabilities. For example, this man described considerable distress and impairment of activity and yet downplayed the problem by comparing himself with those "worse off."

> *Obviously it's affecting my life in a lot of ways at the moment . . . obviously my marriage, sexually, the inconvenience, pain, and everything else that I'm going through. So apart from that you know you've just got to get on with things I suppose. Well, I mean it is it's a lot but there's a lot of people worse off than I am that's the way I look at it.*

In social psychology, this is what is known as "downward comparison": comparing oneself with others to elevate their own health status (Taylor & Lobel, 1989). The idea of "getting on with it" refers to how men tended to opt for private self-management rather than explore curative treatments. This can be seen in the following quote in which the man compares the 20 years he has tolerated urinary difficulties with those who have physical disabilities:

> *There's a lot of people worse in the world when you see the news, people [I: Yeah] limbs missing and 'n erm and they're just getting on with their life and doing different things [quietly] it's the way we are. [sighs] Getting on with it.*

Throughout the interview data, this type of narrative can be seen to underpin stoically tolerating symptoms rather than seeking help. This could be understood as "doing gender through illness" by tolerating symptoms rather than seeking help, because of the sociocultural pressure on men to disassociate themselves from feminine attributes of need and dependence (Courtenay, 2000).

Help-Seeking

We have shown how men with urethral stricture tend to manage symptoms privately, and have argued that this may compound a need to tolerate symptoms. This raises the question: When do patients decide to stop suffering in silence and seek help? All men interviewed had sought medical help at some point, and in the interviews described the moment in which they had decided to "get it sorted" (Wareing, 2005). In many cases, help-seeking was prompted by an escalation in symptom severity such as blood in the urine or incontinence. This supports previous research showing how men typically "put off" seeking help until symptoms became too severe to ignore. In addition, several participants described key events that precipitated a clinic visit. For example, in one interview the participant first described frustration at not being able to attend an important family occasion. His moment to "get it sorted" finally came during an overseas flight when, having spent too long in the airplane washroom, the stewardess came to the door to ask him to leave. On opening the toilet door, he found a queue of people watching him. This was experienced as a moment of intense humiliation and one in which he decided that it was time to "get it sorted." Certainly, patients seek help once symptoms become intolerable, but what is interesting from our analysis is how tolerability is directly related to the patient's capacity to hide symptoms from others. Disease management means balancing the symptoms of urgency and extended toilet visits with the desire to present oneself as normal and free of urinary difficulties. The symptoms of a stricture can cause social embarrassment so, as the above example illustrates, the moment to seek curative treatment often comes when the patient's routines and practices of social concealment are no longer feasible.

Discussion

Previous work has used self-reports from patient questionnaires to indicate that LUTS have a considerable impact on men's quality of life (Andersson, Rashidkhani, Karlberg, Wolk, & Johansson, 2004; Roehrborn et al., 2008), but this effect has not been further explored through qualitative research. Urethral stricture has distinct "bio-psycho-social" dimensions (Kessler et al., 2002) that necessitate subjective understanding of men's lives beyond measurement through questionnaires. Our research provides an insight into the lived experience of men with stricture to show how the need to conceal the condition becomes a central part of how the disease is managed. Urgency, poor flow, and retention are only part of the burden of having a urethral stricture. Having to privately manage symptoms alongside work, friendships, relationships, and travel is an understated and routinized part of living with the disease. As this is a qualitative study, the generalizability of these patients' experiences should be considered with care. However, our findings support previous work on patients with urinary symptoms suggesting that frequent and prolonged toilet visits have practical implications that considerably impact patients' lives, for example, through restless sleep (Coyne et al., 2010) and interruptions to employment and work life (Coyne et al., 2012). Participants in our study described avoiding travel, holidays, or new places, similar to men with an overactive bladder (Coyne et al., 2004). We also found men avoided drinking and limited their activities and social interactions. The evidence supports the previous conclusion that the overall impact of urinary problems is closer to that of chronic conditions such as rheumatoid arthritis (Coyne et al., 2012), but with our results, we can go further to argue that the need to conceal the condition from others is an underappreciated additional stressor. Furthermore, the adoption of self-management rather than help-seeking strategies for men with urethral stricture is compounded by the need for secrecy. The research has benefitted from participants' willingness to discuss aspects of their lives that typically are acutely private. This readiness to share may itself reflect how rare an opportunity this was. Previous studies have also discussed the significance of embarrassment or shame related to disease causing urinary symptoms (Kiviniemi & Suominen, 1999; Shaw, Tansey, Jackson, Hyde, & Allan, 2001; Welch, Taubenberger, & Tennstedt, 2011). However, such research has typically conceptualized embarrassment rather narrowly as a barrier to help-seeking. Our analysis goes further to show that the need to conceal symptoms is itself a source of anxiety and permeates patients' everyday lives. Urinary symptoms can be understood as somewhat stigmatized (Scambler, 2009) as urination and the penis are typically “backstage” topics excluded from social interaction. The symptoms are also “invisible” in the sense that they can often be disguised from others (Joachim & Acorn, 2000). Although it is understandable that urethral stricture patients may wish to keep their condition private, it should be noted that they will miss out on support that patients with other benign conditions may receive. Previous research has found that people in general (Benner et al., 2009; Horrocks, Somerset, Stoddart, & Peters, 2004; Shaw et al., 2001), but men in particular, tolerate urinary symptoms (Cunningham-Burley, Allbutt, Garraway, Lee, & Russell, 1996; Jolleys, Donovan, Nanachahal, Peters, & Abrams, 1994). It has been suggested that such tolerance happens through particular psychological coping mechanisms (Gannon, Glover, O’Neill, & Emberton, 2004). Here we have shown how coping also happens practically through planning and routines. Our finding that men express concerns about being “caught out” and having their condition exposed resonate with previous studies showing greater anxiety around urinary problems felt by men than women (Teunissen, Van Den Bosch, Van Weel, & Lagro-Janssen, 2006). In addition, research has shown that men with benign penile disorders experience shame and embarrassment that reinforce the need to tolerate and “put up with” their condition (Wareing, 2005). We similarly found that men talked about tolerating symptoms and “getting on with it.” This fits with previous research into masculinity and health that has argued that traditional notions of male identity, based on independence and strength, can detrimentally effect men’s likelihood of acknowledging problems and seeking help (Charmaz, 1994; Courtenay, 2000). However, it has also been suggested that help-seeking itself is a gendered form of performativity, enacted as a moment of autonomy, decisiveness, and problem-solving (Charmaz, 1994). Similarly, we found that men’s narrative around help-seeking was that it was time to “get it sorted.” An alternative understanding of men’s help-seeking is that it happens when continuing to tolerate the illness limits the ability to “preserve or restore” enactments of masculinity (O’Brien, Hunt, & Hart, 2005). This too could be said to be supported by the experience of the men in our study who were having problems with work and relationships. However, there is perhaps a risk of over-gendering these findings. An important part of our argument has been how men with urethral stricture conceal and disguise symptoms that, as they involve the penis and urination, are not easily commensurable with the social presentation of self. These men’s identities are maintained by excluding their condition and symptoms from the public sphere through routine, planning, and secrecy. In this sense, the eventual help-seeking happens not because the illness undermines the viability of a masculine identity but because it is no longer possible to separate the condition from the social sphere altogether.

Limitations

The findings presented in this article were emergent from the broader feasibility study which aimed to understand whether the OPEN trial would fulfill its objectives. Therefore, the study was not designed explicitly for the purpose of understanding how men conceal urinary symptoms. The participants interviewed had made different treatment decisions and were at different stages in their illness trajectory and treatment. All of these factors may have influenced their accounts of their experience. Similarly, the men described here represent a broad range of ages, sociocultural contexts and other demographics. However, despite the demographic differences, we found similar narratives and attitudes regarding symptom management through concealment. A further limitation is that the sample necessarily only included men who have presented their symptoms; there will be a population of men with urethral stricture who have yet to seek clinical help for their symptoms who may display different attitudes and behavior.

Conclusion

The private life of managing urinary symptoms is something that health professionals rarely have the opportunity to see. A key finding from this research is that men's management of urethral stricture is inextricably related to the need to conceal symptoms and manage an appearance of normality, for example, through planning and routines. We suggest that the tendency to hide urinary problems raises issues not just of help-seeking, but about an unseen emotional burden. It is not until men with urethral stricture feel that concealment is no longer tenable that presentation to a health professional occurs. The social and behavioral adjustments that men make to enable them to "live with" urethral stricture symptoms should be considered by health professionals during clinical assessment to enable shared decision making around treatment options and their potential impact on an individual's well-being and activities.

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