

## CHAPTER 11

# Experiences of Sexual Rehabilitation after Prostate Cancer

## A Comparison of Gay and Bisexual Men with Heterosexual Men

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### CHAPTER SUMMARY

In a study of sexual rehabilitation after prostate cancer, gay and bisexual men (GBM) were more likely than heterosexual men (79% versus 56%) to report having tried medical or other aids to address erectile dysfunction. GBM were also more likely to have tried more than one medical aid (GBM  $M = 1.65$  aids, heterosexual men  $M = 0.83$  aids), including medication, penile injection, penile implant, and vacuum pump, and to have sought information about sexual rehabilitation after prostate cancer on the Internet, through counseling, or through a support group. There were no differences between the groups in satisfaction with the use of sexual aids. Accounts of satisfaction described medical and sexual aids as indispensable in maintaining sexual functioning and relationships. However, the majority of men in the study described hindrances, both physical and social, associated with using medical or sexual aids, which resulted in discontinued use of such aids. These barriers were the perceived artificiality of medical and other sexual aids; loss of sexual spontaneity and necessity to plan for sex; physical side effects; failure to achieve erectile response; financial cost; and lack of access to sexual rehabilitation information and support.

### KEY TERMS

erectile dysfunction, medical aids, penile implant, sexual aids, sexual rehabilitation, vacuum pump

## INTRODUCTION

In the context of erectile and other sexual changes experienced by gay and bisexual men (GBM) and other men who have sex with men (MSM) after prostate cancer,<sup>1, 2</sup> researchers and clinicians have identified a need to help individuals and couples reestablish their sexual lives.<sup>1, 3-6</sup> Some attention has been paid to “renegotiation”<sup>2</sup> or “reframing”<sup>5</sup> of sexual activities, such as the development of “flexibility”<sup>7</sup> in relation to sexual practices.<sup>5</sup> In comparison with heterosexual couples coping with prostate cancer, gay couples are more likely to engage in novel practices to deal with sexual challenges following treatment, such as engaging in concurrent sexual relationships<sup>8</sup> or a change in sexual mode or position from insertive to receptive.<sup>7</sup> However, little is known about differences between gay and heterosexual men in adoption of medical or sexual aids for sexual rehabilitation following erectile difficulties.<sup>5</sup>

Sexual rehabilitation after prostate cancer has most often focused on regaining erectile function to improve sexual satisfaction and penile health.<sup>5</sup> Common biomedical interventions for erectile dysfunction or penile rehabilitation include PDE5 inhibitor drugs (e.g., Cialis, Viagra, and Levitra), penile injection therapy, penile implant (i.e., surgical prosthesis), and vacuum pump erection devices (see chapter 10). Approximately half of prostate cancer patients report using a medical aid for penile rehabilitation after prostate cancer treatment.<sup>9, 10</sup> However, despite reports of gains in penile rigidity, up to 73% of patients discontinue using these aids within the first year.<sup>5</sup> Little is known about why couples abandon the use of aids; there is a need for more research in this area.<sup>11</sup> It has been suggested that reasons for discontinuation include difficulties achieving erectile firmness that is equivalent to that experienced before treatment or that required for penetrative sex;<sup>12</sup> a mismatch between treatment effectiveness and patient’s expectations for recovery;<sup>13</sup> a sense that use of aids results in unnatural and obligatory intercourse;<sup>14</sup> limited motivation from some partners regarding sexual recovery;<sup>15</sup> and lack of ongoing information and support across the disease pathway to address difficulties with rehabilitation when they arise.<sup>16</sup> However, many of the published accounts of patient experience of sexual rehabilitation after prostate cancer are based on clinical vignettes, and there is a lack of literature reporting on men’s subjective experiences of sexual rehabilitation to support treatment recommendations and delivery of care.<sup>11</sup>

Sexual rehabilitation research and recommendations also focus almost entirely on heterosexual samples and vaginal intercourse, neglect-

ing anal intercourse and the sexual rehabilitation needs and experiences of GBM with prostate cancer.<sup>3, 17</sup> As just one example, it has been suggested that first-line oral therapies may be less effective for GBM adopting an insertive role during anal intercourse because firmer erections are required for anal sex than for vaginal sex.<sup>18</sup> To date, however, there is no published research on how many GBM, in comparison to heterosexual men, adopt medical or other aids for sexual rehabilitation, and there has been only one study examining GBM's experiences of sexual aids after prostate cancer.<sup>19</sup> This chapter presents the findings of a study that compared GBM and heterosexual men with respect to the use of medical and other sexual aids after prostate cancer.

## THE STUDY

One-hundred and twenty-four GBM and 225 heterosexual men who currently have, or have had, prostate cancer participated in an online survey, and 73 took part in semistructured interviews (53 GBM and 20 heterosexual men), part of a larger program of mixed-methods research examining sexual well-being and quality of life after prostate cancer.<sup>2, 20-22</sup> The GBM were significantly younger than the heterosexual men (GB 64.25 years; heterosexual 71.54 years), less likely to be partnered (GB 50%; heterosexual 86%), less likely to report a current relationship of over two-year duration if partnered (GB 81%; heterosexual 93%), and more likely to have casual sexual partners (GB 40%; heterosexual 4%). Prostate cancer had been diagnosed 5.9 years previously for GBM and 7.7 years previously for heterosexual men; diagnosis resulted in a range of treatments, and the majority of participants were at the time of the survey being monitored after treatment.<sup>20</sup> Participants were primarily recruited in Australia (71%), and a minority were recruited from the United States (21%) and the United Kingdom (8%).

GBM were significantly more likely to report having tried medical or other aids to address sexual dysfunction than heterosexual men (73.4% GBM, 51.1% heterosexual men) (table 11.1) and having tried more than one aid (GBM  $M = 1.65$  aids, heterosexual men  $M = 0.83$  aids), including medication, penile injection, penile implant, vacuum pump, and other aids (e.g. cock ring, dildo, vibrator). GBM were also significantly more likely to have sought information about sexual rehabilitation after prostate cancer on the Internet, through counseling, or through a support group. There were no differences between the groups in satisfaction

with the use of sexual aids and no differences between partnered and unpartnered men in the use of aids.

In the accounts below, we examine descriptions of successful and unsuccessful sexual rehabilitation, drawing on open-ended survey responses and interviews, analyzed through thematic analysis.<sup>23</sup>

### **SUCCESSFUL SEXUAL REHABILITATION: "THERE IS NO WAY I WOULD HAVE FUNCTION WITHOUT IT"**

A minority of both heterosexual men and GBM reported satisfaction with using one or more medical aids after prostate cancer (table 11.1). Positive accounts focused on increased erectile function and improved penile form. For example, participants said: "It [Cialis] has been 100% effective. . . . There appeared to be no way I would have been able to have any function without it" (Billy, gay, partnered, 72); "It [Cialis] restored some of the feelings that I had. . . . The penis was stuffed but it was working" (Brad, heterosexual, partnered, 75); "I've used that [vacuum pump] fairly regularly and that has made a difference, both to my satisfaction with penile length as well as the feeling of consistency in my penis" (Bruce, gay, partnered, 61).

Participants who used a combination of medical and sexual aids often described increased erectile response. For example, Connor (gay, partnered, 61) reported using a vacuum device and Cialis alongside penile vasoconstriction devices (colloquially described as "cock rings" and "lassoes"): "There was some healing happening. . . . There was no longer just a soft penis, kind of, struggling with that, there was actually sensation in the masturbation again and the penis was inflated enough to look like my penis." Positive responses to the use of medical aids included "pleasurable" and "intensely satisfying," and the use of such aids was often reported to lead to incorporation of additional aids to support pleasure during sex. For example, Elliot (heterosexual, partnered, 64) described using a vibrator for "extra help" to achieve an erection and to receive anal pleasure: "I think it just sort of increases the intensity of it. . . . You're trying to sort of generate pleasure from some part of your body, and that's an area that's quite sensitive and I was able to get something else out of." Harry (gay, partnered, 71) said, "We use toys a bit and the vibrator, which helps me a lot to get me going" to support pleasure during sex. Jonny (bisexual, partnered, 54) told us he had developed an interest in a variety of sexual aids, including erotic

**TABLE 11.1**

Nonheterosexual versus Heterosexual Men: Sex Aid Use and Satisfaction

	Nonheterosexual		Heterosexual	
	<i>N</i> = 124		<i>N</i> = 225	
Variable	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Number of different aids tried	1.65	1.39	0.83	1.05
<b>Types of Aids Tried</b>	<i>n</i>	%	<i>n</i>	%
Oral medication***				
Yes	82	66.13	85	37.78
No	42	33.87	140	62.22
Penile injection**				
Yes	32	25.81	30	13.33
No	92	74.19	195	86.67
Penile implant*				
Yes	11	8.87	8	3.56
No	113	91.13	217	96.44
Vacuum pump***				
Yes	33	26.61	24	10.67
No	91	73.39	201	89.33
Other sex aids or "toys" (e.g., vibrator, dildo, cock ring)***				
Yes	44	35.48	36	16.00
No	80	64.52	189	84.00

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Variable	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Number of different aids tried	1.65	1.39	0.83	1.05
<b>Sexual Aids Satisfaction</b>	<i>n</i>	%	<i>n</i>	%
Oral medication satisfaction				
Dissatisfied	31	47.69	41	64.06
Neither satisfied nor dissatisfied	12	18.46	4	6.25
Satisfied	22	33.85	19	29.69
Penile injection satisfaction				
Dissatisfied	13	41.94	19	70.37
Neither satisfied nor dissatisfied	2	6.45	1	3.70
Satisfied	16	51.61	7	25.93
Penile implant satisfaction				
Dissatisfied	3	33.33	2	50.00
Neither satisfied nor dissatisfied	5	55.56	—	—
Satisfied	1	11.11	2	50.00
Vacuum pump satisfaction				
Dissatisfied	13	46.43	10	50.000
Neither satisfied nor dissatisfied	10	35.71	3	15.00
Satisfied	5	17.86	7	35.00

*(continued)*

**TABLE 11.1** (continued)

Nonheterosexual versus Heterosexual Men: Sex Aid Use and Satisfaction

	Nonheterosexual		Heterosexual	
	N = 124		N = 225	
Variable	M	SD	M	SD
Number of different aids tried	1.65	1.39	0.83	1.05
<b>Support from Formal or Informal Sources</b>	<i>n</i>	%	<i>n</i>	%
Internet***				
Yes	46	37.10	28	12.44
No	78	62.90	197	87.56
Psychotherapy/counseling***				
Yes	17	13.71	4	1.78
No	107	86.29	221	98.22
Support groups***				
Yes	31	25.00	14	6.22
No	93	75.00	211	93.78

Significance level of difference between groups, chi squared: \*p < .05; \*\*p < .01; \*\*\*p < .001

electrostimulation, a vibrating vacuum pump, an anal plug, and latex accessories used in bondage: “I’ve taken quite an interest in trying out different things,” including “e-stim,” “milking machines,” “butt plugs,” and “vac-racks.” The use of sexual aids appears to serve multiple functions, including increase of pleasure, taking the focus away from the penis, supporting or enhancing arousal, and facilitating sex. Paradoxically, the loss of erectile function may have led men to broaden their exploration of sexual pleasure through aids that stimulate multiple sites of the body, an exploration that might not have come about without loss of penile function and form.

The utility of medical and other aids was most often described in terms of whether they made intercourse possible, increased sexual confidence, and facilitated sex with regular partners. For example, Rick (gay, partnered, 59), as a result of using Cialis, Viagra, and a cock ring, said, "I have been able to have penetrative sex with my partner, which has been great for him and for me." Darryl (heterosexual, partnered, 65) observed: "When you're having sex, you can go as long as you like. . . . It [the penile implant] works perfectly every time. . . . It's given me a lot more confidence and it's meant that we've been able to be much more intimate."

A number of participants, particularly GBM, also reported that medical and other aids enabled them to pursue casual sexual encounters. For example, Michael (gay, single, 69), who took Cialis and used a cock ring, said, "I just disappear into the toilet and give myself an injection, and then I have got an erection for about an hour or an hour and a half, and that can be rather good." The downside was that Michael had to take along his "gear" when going out: "Let's say I met somebody and I didn't have my gear with me, then it becomes much more difficult." Use of oral medication was more straightforward in terms of planning, as Oliver (gay, single, 66) said: "It works wonderfully well [laughs] for me. That's all I need—half a Viagra—when I'm going out, to have a good time." Mark (gay, single, 45) described how the consistent erection he achieved through his penile implant supported his inclusion within a gay sexual community: "I think the disqualification [from a gay sexual community], historically, was much worse. That's been replaced, you know, because I can function sexually with the pump [penile implant]." Graham (gay, single, 74) described being "proud" of his penile implant, which enabled him to go to saunas "where a man with an erection is sought after and highly valued, and I go there, because I can do it." Graham had been given the nickname "Robocock," and he associated openness and lack of embarrassment with a positive outcome in relation to casual sexual partners: "One of the differences between gay sex and straight sex is it is much more up-front and personal and close. I mean, a man will either just grab you by the balls and he will feel this horrible thing and just go and run screaming into the night. But, if I talk about it first, and I defuse that, then they become intrigued by it and very understanding." Graham's comment about "defusing" potential negative reactions from partners illustrates the importance of confidence and a positive attitude toward medical and sexual aids, particularly in the context of casual sexual interactions.

### **ARTIFICIALITY, FAILURE, COST, AND SIDE EFFECTS: NEGATIVE EXPERIENCES OF MEDICAL AND OTHER SEXUAL AIDS**

While some men reported success and satisfaction using aids, most men experienced hindrances, both physical and social, associated with using medical or other sexual aids. As a consequence of these hindrances, many participants described discontinuing use of such aids. These hindrances were the perceived artificiality of medical and other sexual aids; loss of sexual spontaneity and necessity to plan for sex; physical side effects; failure to achieve erectile response; financial cost; and lack of access to sexual rehabilitation information and support.

**The artificiality of an assisted erection.** The description of medical and other sexual aids as artificial was evident in both heterosexual men's and GBM's accounts. Achieving erectile functioning through penile implants or injections was described as "more mechanical" and "really artificial," where "the naturalness has gone." Comparisons were made that positioned nonassisted erections as superior and "real." For example, Graham (gay, single, 74) said: "I really miss that first flush of excitement when I was younger and I used to get turned on by something or other. . . . Now it's not natural, I just press a button and I'm turned on." Similarly, Scott (gay, single, 59) said his erection is "something that I've lost" and described the difficulty of injecting at sex-on-premises venues among other men who have an erection: "I've got the hand on the container and the swab and the lights and the toilet and when I'm sort of just sitting around waiting for something to happen, you start watching other guys going backwards and forwards, the thought bubble says, 'Boys, you have no idea how lucky you are to have your own hard-on.'" Scott, who stated he no longer perceived his erection to be his own, described a qualitative difference in the type of erection experienced. The external assistance he received produced a poor "imitation" of an erection, one he described as "not real" and feeling "artificial" to him.

For some men, the reliance on sexual aids to achieve an erection challenged their sense of being a man. For example, Darryl (heterosexual, partnered, 65) said, "You lose some of your manhood somewhere along the way. You feel less of a bloke because you can't get it up or you've got to rely on this artificial device." Billy (gay, single, 75) described himself as "damaged goods," and the experience as "cheap and nasty," when he "had to take a tablet" after a prospective partner said to him, "'Look, let us go. Let us have some fun.'" Neil (heterosexual, partnered, 68) said the experi-

ence of having to “make a conscious decision” to inject for an erection was inferior. He added: “Having an erection is not just signaling that I’m capable, it’s actually a message to both of you, a subliminal message that everything is okay. I’m relaxed, I’ve got an erection. It means I can have sex, it means I’m healthy, it means a lot of things. And what I realized is that the erection just isn’t about being able to penetrate, it’s about, it’s about a bloke saying everything is okay, I’m right, I’m healthy, here I am.”

These men, both heterosexual and gay or bisexual, here reveal that dealing with erection problems—the central and most frequent side effect of prostate cancer treatment—is a loss, a diminution of pleasures, and damage to a sexual sense of self. These problems are relentless and ongoing because, while medical and sexual aids offer some respite from those problems, they do not fix them. Lee and colleagues describe this feeling as one of being “compromised,” and no amount of accommodation to the aids available to men will adequately replace what has been lost.<sup>24</sup>

**Loss of sexual spontaneity.** The accounts of artificiality frequently noted a loss of spontaneous sexual activity since treatment. Many men described their earlier “natural” or spontaneous erections as having instigated sexual encounters, the loss of which led to challenges initiating sex and to difficulties with sexual communication. Using medical aids during the sexual encounter was described as “a passion killer,” “impersonal,” and “clinical, not romantic” because “you had to plan ahead if you were going to have sex” or “stop in the middle of making love.” Participants described this lack of spontaneity as an “interruption.” For example, Sid (transgender, heterosexual, married, 64) said: “You’ve got to preprogram it all. Even with the injections, you get a bit amorous and what have you, you say let’s have sex, hang on a moment, I need an injection, then you’ve lost it.” Neil (heterosexual, partnered, 68) noted, “The lack of the spontaneous trigger or signal of an erection seems to reduce the ardor.” As a result of loss of spontaneity and the need to plan sexual encounters, Jonny (bisexual, partnered, 54) said he no longer instigated sex: “I wait more for signals from my wife that she would like to have sex rather than springing a surprise on her and then find that it’s just not a good time.” In contrast, Billy (gay, partnered, 72) said, “It was always me that instigated it before because I was the one that was damaged goods. . . . He didn’t know whether I was ready or not.”

The loss of spontaneity associated with using specific medical aids

was described as especially problematic for casual sexual encounters and for dating. Using penile injections was highlighted as particularly so. "The logistics of injecting in casual sex situations is a complete joke. I mean, it's abhorrent" (Mark, gay, single, 45). "It's not the easiest thing to do discreetly, you're puncturing your dick, which means you have an open wound, which means there's blood there, and that invites a certain extra level of risk" (Scott, gay, single, 59). "Having to use the injection therapy is a big hurdle. It's hard enough meeting people, especially females, and trying to establish a good, healthy friendship with them, which includes hopefully some sex, when you know that this hurdle's there" (Brian, heterosexual, single, 63). These reflections suggest that the flow of encounters well understood by these men is disrupted by the use of medical aids, particularly in casual sexual encounters, and may ruffle the expectations of partners: users of medical aids are on their own, having either to use aids discreetly to avoid this disruption, or to disclose to partners and hope for an accepting or patient response.

**Physical side effects.** The side effects and complications associated with use of medical aids were frequently reported. As a result of these side effects, participants described enduring or forgoing the use of medical aids.

PDE5 inhibitor tablets were reported by many participants to result in frequent headaches, nausea, and disorientation. For example, one man told us: "I took the full Viagra and I got so disorientated and I went to bed. And then I thought I'd better get up and have a shower and I got up and I vomited everywhere" (Drew, gay, partnered, 65). "I had all the three different types of pills . . . all it did was make me have these incredible hot flushes and everything would turn blue and I'd have thumping headaches" (Jim, heterosexual, partnered, 58). For these men, such side effects outweighed the benefits of using PDE5 inhibitors. Damon (gay, single, 52) ruminated: "Do I wanna take a tablet, and wait 45 minutes and have that, what I find sometimes rather unpleasant, flush to the head feeling, and then urinate, and then have a wank. . . . Sometimes I think, oh, you know what, can't be bothered."

Penile injections were described as causing physical pain during and following use, and prolonged use of penile injections was associated with penile curvature and deformity. For example, participants said that "the comedown from the injection was not very comfortable; it was quite painful" (Bruce, gay, partnered, 61); "Too much muscle in

penis turned to gristle. Now can't continue with aid" (Alf, gay, single, 55). In addition, penile injections occasionally resulted in priapism for some men, including Darryl (heterosexual, partnered, 65), who described "finishing up in accident and emergency" and waiting "seven hours by the time they got it down." He added, "It's the most embarrassing thing in my life," after which he noticed he was "getting a bit of a bend in my penis when it was erect, and it had caused scarring." Drew (gay, partnered, 65) described his one experience of penile injection as "hopeless" because he had an "intense erection for about four hours," which left him thinking, "No, never again, and I certainly wouldn't recommend them to anyone." Other participants focused on the pain of the injection itself: "Penile injections hurt too much, feel that the pain was not worth the erections" (Henry, gay, single, 56); "I just find it's far too much pain to be actually bothered with it" (David, gay, partnered, 64).

The negative side effects of the penile implant were described by some men as penile shortening and difficulty reaching orgasm. For example, Darryl (heterosexual, partnered, 65) said: "The penile implants shorten your penis. . . . They knock about two, two and a half, three centimeters off the length, and that could be hard for a bloke to take, too." This is a matter of concern given that many men report worries about penis size after prostate cancer treatment and before using medical and other aids<sup>2,17</sup> (see chapter 2). Mark (gay, single, 45) said, "Before the implant, I mean, with no erection at all I could still reach orgasm," whereas during the surgery for the procedure "that all got chopped out, that's all gone"; he added, "While I now technically have sexual functioning, I have considerably impaired sexual satisfaction."

In addition, the presence of a mechanical pump within the scrotum when using the penile implant often led to a negative response from partners. For example, Mark (gay, single, 45) told us: "[Casual sexual partners] do feel [the pump] in the scrotum, and you can see they do a very definite nonverbal pause. . . . A couple of people will then have stopped the sexual encounter. Other people have continued but seem wary of it." Darryl (heterosexual, partnered, 65) said, "[My wife] doesn't like the feel of it, because the pump's inside the scrotum. . . . Once upon a time she would have fondled me down there, she doesn't like it because it's all, all bumpy with this plumbing in it." An additional concern was also raised by Graham (gay, single, 74): "The implant doesn't cover the full length of my penis, so there is a bit of a droopy tip. So I always say it's a bit like a Concord taking off, you know, the sort of wobbly thing at

the end which makes insertion a little bit harder . . . especially for a gay man and would probably be easier for a straight man.” Graham’s experience suggests that men may require further assistance or information to make effective use of the implant. For Graham, this was an unsupported process of trial and error: “At first it [insertion] was just really difficult,” whereas later “I have learned how to deal with that, just by pulling back on the skin.”

**Medical aids do not work.** Many participants reported that they tried using medical aids after prostate cancer treatment but found them ineffective. Participants reported attempting a range of medical aids with unsatisfactory results. There were several examples: “Oral medication, tried them all, nil results. Penile injections, tried 10 and 20 Caverject and 10/20 double injections, nil result” (Angelo, heterosexual, partnered, 64). “I’d used [PDE5 inhibitors] on and off over the years leading up to the cancer. It worked maybe 70 to 80% of the time. Now they don’t work at all, the pills are useless” (Henry, gay, partnered, 59).

Other participants reported some effect from medical aids, but some, such as Jonny (bisexual, partnered, 54), noted that it was temporary: “The effectiveness [of the penile injection] is beginning to wear off so it’s not giving as good erections now as it did initially, so I’m concerned long-term — am I going to even lose this opportunity of getting a decent erection?” After a lack of response from PDE5 inhibitors, Mark (gay, single, 45) said, “I got a climax injectable, and the first time I used it, it worked profoundly well. It was fantastic. I thought, God’s gift, you know? And it never worked again after that.” These accounts suggest that a number of men were prepared to experiment with a range of medical aids, but that in at least some cases, the effectiveness was temporary.

**Cost of medical aids.** Participants who described achieving a positive erectile response from medical aids often reported that the “mighty expense” of the aids was a barrier to continued use in contexts in which the costs were not covered by personal health insurance or national health support. For some Australian men, this expense was too difficult to meet: “Injection was extremely successful but is now too expensive” (Adam, gay, single, 60); “Cialis, that works and it worked well. . . . But then after I retired of course I didn’t have quite the income that I had before, so I gave them away” (Hugh, heterosexual, partnered, 73). For other participants, use of medical aids was often a careful financial

decision that involved a trade-off with other expenses. For example, Nick (bisexual, single, 66) told us, "I can afford them, but a couple of years down the track, who knows, I might want to direct that money into something else"; Robert (gay, partnered, 66) observed: "When I go onto Cialis for the whole month, it [erectile functioning] starts to approach where it used to be, but I've got to again find that money to actually do that. So that means I just go without doing something else to have that. Often I think I'd much rather go out and have dinner."

While Viagra is now off patent and much lower in price in many places, other PDE5i drugs are not. National health schemes and private or public health insurance plans sometimes cover some of the cost, but not in all countries or uniformly. The issue of cost and lack of subsidy for many men living with erectile difficulties after prostate cancer treatments is an ironic example of how "masculinity," often equated with erections in the prostate cancer field, does not seem to signify much to mostly male politicians and governments.

**Absence of information and support.** Across the sample, there were inconsistent accounts regarding the amount of information and support provided by health professionals for sexual rehabilitation, and specialist referrals were offered only to a minority of men. For example, Aaron (gay, single, 59) said he was referred to a sexual rehabilitation specialist before surgery and over a course of months was placed on "a program" of Cialis, Levitra, penile injections, and vacuum pumping: "I've almost done it like as if it's the therapy. It's like the doctor's orders. . . . I do it as a mechanical exercise . . . and I have to say there's been a slight improvement." As a consequence of "following this program," Aaron said, "that's why, psychologically, I haven't been depressed or anything."

Conversely, participants who did not engage with timely sexual rehabilitation often regretted missing opportunities to preserve sexual functioning: "The vacuum pump should be advised and used early after the operation, to help in the repair of the erection process. I may have left it too long, but that was the advice" (George, heterosexual, single 56); "I would've appreciated an immediate introduction to the notion of a penile rehabilitation program because I had to discover all that myself, after my surgery" (Bruce, gay, partnered, 61). Lack of sexual rehabilitation support was associated with lower prostate cancer treatment satisfaction by some participants. For example, Brian (heterosexual, single, 63) reported lack of interest from his urologist in addressing his sexual

challenges following treatment: "I just got the impression that my bloke [urologist] didn't want to dig into that area much at all. Like, he'd done his job and he considered it was successful and he was not that keen to get involved with me there." Other men talked of distressing interactions with healthcare professionals when rehabilitation was offered. For example, Graham (gay, single, 74) described "feeling like an object" when his urologist demonstrated his penile implant to a "strange lady" without asking permission to do so: "When I was in hospital after the penile implant, I was just lying there in bed with my— my puffed-up penis, all wrapped up in bandages, and the doctor just walked in, the urologist walked in, with some strange lady that I had no idea who she was, and without saying anything, he just grabs my bandaged thing and undid it and demonstrated how you puff it up. And I was really put out by that."

Gareth (gay, single, 65) asked his doctor what he could do to address reduced penis size and was told "I don't want to know anything about your sex life." The lack of healthcare professional knowledge of the effect of prostate cancer on gay sex is a concern for many GBM, in relation to anal sex, reduction in penis size, the prostate as a site of pleasure, and absence of ejaculate, all mentioned as areas where rehabilitation information had been sought but was not forthcoming<sup>21</sup> (see also chapters 2, 3, and 6).

## **CONCLUSION**

The findings of this study show the challenges and diverse reactions that heterosexual men and GBM experience in using medical and other sexual aids following prostate cancer treatment. GBM were more likely to try sexual aids, to use a range of aids, and to move from one aid to another if they were not satisfied with the results, regardless of relationship status. They are also more likely to seek information and support about sexual rehabilitation from informal and formal sources. This search for information may reflect the greater importance placed on sex and sexual functioning by GBM and their partners,<sup>25, 26</sup> their greater openness to using sex aids and toys,<sup>27, 28</sup> and the higher levels of distress and sexual bother associated with sexual dysfunction in gay and bisexual men following prostate cancer treatment<sup>4, 20</sup> in comparison to heterosexual men. Interest in and willingness to use sexual aids may also reflect GBM's greater openness to sexual experimentation,<sup>29</sup> and can lead to renegotiation of sexual activities in the context of cancer.<sup>2, 7, 8</sup> GBM may also have a greater willingness to communicate with

their partners about sexual changes or difficulties,<sup>2</sup> and couple communication is key to achieving sexual functioning after cancer.<sup>30</sup> Further research is needed to examine couple communication about sexual rehabilitation in GBM and heterosexual men.

A substantial proportion of both heterosexual men and GBM reported dissatisfaction with medical and other sexual aids, which is consistent with previous reports on heterosexual men.<sup>5,31</sup> There was a high degree of variability in dissatisfaction with specific aids, which suggests that individual differences need to be taken into account, regardless of sexual identity. These differences imply that support provided to help couples use assistive aids effectively and consistently needs to go beyond the mechanics of sexual aids, or the achievement of an erection, to incorporate the meaning of sex and sexual aids, along with individual coping strategies.<sup>5</sup> Schover and colleagues suggest there is a need for support in development of more timely and realistic expectations of the use of aids.<sup>32</sup> These expectations can be incorporated into sexual counseling, focusing on areas such as increasing communication and stimulation skills, ideally offered as part of the routine care offered to couples after prostate cancer treatment.<sup>11</sup> It has also been argued that the couple should be the focus of treatment, where possible, to enable shared ownership of the treatment and provide the potential for eroticization of the treatment itself.<sup>5</sup>

The specific needs and concerns of GBM associated with sexual functioning after prostate cancer should be taken on board by clinicians offering advice about rehabilitation.<sup>17, 33</sup> The eroticization of ejaculation for many gay men<sup>2</sup> suggests that treatment for prostate cancer may be inherently distressing because of the absence of ejaculate after treatment.<sup>4</sup> The likelihood that anal sex requires firmer erections than vaginal sex has led some researchers to propose that providers should educate GBM about the limitations of oral therapies for erectile dysfunction and consider more invasive treatments sooner.<sup>4</sup> Assessment and treatment of rectal damage after prostate cancer treatment is an important area of concern for GBM who adopt a receptive position during anal intercourse. This concern is often neglected in primary care, and until recently it was absent from rehabilitation research.<sup>17, 34</sup> It has previously been reported that heterosexual men are more likely to try assistive aids if they are currently in a relationship, particularly if their partner has good sexual function and is younger.<sup>32</sup> Our findings suggest that there was no difference between partnered and unpart-

nered men in use of sexual aids. Many GBM are also using assistive aids in casual sexual encounters, which presents specific challenges associated with the practicalities and negotiation of use of such aids. Finally, because GBM are more likely to report difficulties in communicating with healthcare professionals about sex and sexual rehabilitation<sup>21</sup> (see chapters 3, 6, and 8), there are clearly unmet needs in this area.

Delaying the start of penile rehabilitation after radical prostatectomy is associated with poorer outcomes for erectile functioning,<sup>35, 36</sup> which suggests that information about medical and sexual aids should be provided at diagnosis, or at least before treatment.<sup>5</sup> Providing this information early may serve to increase satisfaction with and efficacy of medical sexual aids, with positive implications for psychological well-being and the maintenance of relationships after cancer (see chapters 2–6). However, medical and other aids should not be seen as the sole solution to sexual challenges after prostate cancer treatment. Sex therapists can help men who are open to changing their sexual repertoire to include new activities and substitute practices, and to experiment with alternative modes of positioning, improve communication with sexual partners, and negotiate role changes.<sup>34</sup> Because GBM are more likely to report sexual renegotiation or flexibility,<sup>8</sup> as well as the use of medical and sexual aids (see chapter 10),<sup>27, 28</sup> heterosexual men and their clinicians may have something positive to learn from GBM's experience in addressing the sexual challenges and recovery after prostate cancer treatment.

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