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What Gay and Bisexual Men Treated for Prostate Cancer Are Offered and Attempt as Sexual Rehabilitation for Prostate Cancer: Results from the *Restore* Study

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Study received university human participants protection program approval.

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Abstract

Introduction: This is the first known study to investigate what gay and bisexual men are offered and what they try as rehabilitation to address the sexual and urinary effects of prostate cancer treatment.

Methods: A total of 193 gay and bisexual men with prostate cancer were recruited from a large male cancer survivor support and advocacy website. Online participants completed survey questions asking what rehabilitation treatments were offered, what they tried and what their satisfaction was with outcomes.

Results: Most participants (68.4%) reported being out as gay/bisexual to at least 1 cancer specialist. Only 8.8% reported that a sexual history was taken. The most common problems reported were loss of ejaculate (93.8%), erectile difficulties (89.6%), change in sense of orgasm (87.0%), loss of sexual confidence (76.7%), changes to the penis (65.8%), increased pain in receptive anal sex (64.8%), urinary incontinence not related to sex (64.2%) and urinary incontinence during sex (49.2%). Of these factors only loss of ejaculate, erectile difficulties and nonsexual urinary problems were commonly discussed by clinicians during prostate cancer treatment. Satisfaction with specific rehabilitation options varied widely.

Conclusions: Treatment for prostate cancer lacks adequate history taking and consensus around rehabilitation practices, resulting in idiosyncratic approaches to rehabilitation. Four clinical questions may improve outcomes. Prostate cancer specialists need education to become culturally competent in addressing the unique needs of gay and bisexual patients.

Keywords

prostatic neoplasms; sexual and gender minorities; erectile dysfunction; urinary incontinence; sexual behavior

Prostate cancer is the second most common cancer among men in the United States, with a reported 2,795,592 living with prostate cancer in 2012.[1] With an estimated 220,800 new cases diagnosed in 2015 the disease has an incidence similar to breast cancer in women.[1,2] Leading risk factors are age and familial history of prostate cancer.[1,3] Racial and ethnic disparities are also evident. However, precise estimates of prostate cancer diagnoses by sexual orientation do not exist.

The Centers for Disease Control and Prevention estimates that 3.5% to 4.4% of men in the U.S. have had sex with a man in the last 5 years,[4] of whom 40% to 60% are in sexual relationships.[5,6] By extrapolation between 97,845 and 123,006 gay, bisexual and other men who have sex with men are living with a diagnosis of prostate cancer, including 39,138 to 73,804 men in male couples.

Sexual and urinary dysfunction are the 2 most common problems following prostate cancer treatment. In heterosexual men reported rates of urinary dysfunction were 8.4% and 14.0%, and rates of sexual dysfunction were 59.9% and 72.0%, respectively, at 18 months and 5 years after treatment.[7,8] Prostate cancer in GBM remains markedly under researched,[9,10] resulting in health disparities.[11] While studies have begun to document sexual and urinary dysfunction rates in GBM,[9,12,13] we could find no published studies on what GBM are

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offered or try as part of sexual recovery following prostate cancer treatment. To address this gap in research, as part of a larger study investigating the sexual, mental and social effects of prostate cancer treatment in GBM, we conducted an inventory of rehabilitation methods offered to and tried by GBM following treatment for prostate cancer.

Materials and Methods

We conducted the *Restore study*, a National Cancer Institute funded, online survey study of the "Sexual Effects of Prostate Cancer in Gay and Bisexual Men" in 2015 and 2016. Recruitment was through Malecare, the largest male cancer support group and advocacy organization in North America. Participants, who were recruited through organizational email, LISTSERV and social media, clicked on a link to access the study. Eligible participants were confirmed using an online screener as 1) male, 2) age 18 years or older, 3) identifying as gay, bisexual or a man who has sex with men, 4) English speaking, 5) living in a U.S. or Canadian residential zip code and 6) diagnosed with and treated for prostate cancer. For consent enrollees were required to review and affirm 7 screens detailing study purpose, risks, benefits, payment preferences and identity. A semiautomated cross-validation and deduplication protocol was used to flag and investigate suspect surveys.[14] Data collection lasted from October 2015 to January 2016 (71 days). Each participant received a $50 gift card for completing the 30 to 45-minute survey. All study procedures were approved by our university human participants protection program.

The recruitment protocol for this study is detailed in our companion article.[15] To summarize, we received 502 click-throughs to our welcome page, with 434 participants (86.5%) passing eligibility and 417 (96.1%) consenting to participate. The deduplication and cross-validation protocol rejected 233 surveys as suspicious, leaving 194 (46.5%) deemed to be from unique, valid participants. Of these surveys 193 (99.5%) were completed, comprising the final study sample.

Measures/Instruments

The survey questionnaire contained items on 15 topics including demographics, history of prostate cancer treatment, sexual rehabilitation history, sexual and urinary functioning and a needs assessment. To minimize participant burden, skip and branch patterns were used. Most participants answered around 150 questions.

Given the lack of research in this area, questions on treatments were developed by the authors based on in-depth interviews with 31 GBM treated for prostate cancer. The wording of questions is detailed in supplementary table 1 (http://jurology.com/). An introductory question examined whether a sexual history was taken before the most recent treatment. Then participants were asked which of 12 potential problems were discussed before treatment and which they actually experienced. Response options for all questions were "yes," "no," "don't know/don't remember" and "refuse to answer." Participants were next asked to identify which of 11 treatment options were discussed and which options they actually tried. For items such as Kegel exercises and vacuum pump supplementary questions examined the frequency of exercises recommended, the frequency undertaken and the

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duration. Finally, for those rehabilitation options tried satisfaction was measured with a single 5-response Likert-type item from “very unsatisfied” to “very satisfied.”

Analysis

All analyses were conducted using Stata®. Quantitative analysis was straightforward and mainly used frequency counts. In comparative analyses 5-point Likert-type items were treated as continuous data and analyzed using 2-tailed t-tests and regression analyses. For categorical data chi-square analyses were used. Given the number of analyses, a priori we set significance at $p < 0.01$ and evidence of trend at $p < 0.05$.

Results

The demographic, sexual and medical characteristics of the participants are detailed in supplementary table 2 (http://jurology.com/). To summarize, the typical participant in this study was a white non-Hispanic, well educated male in his 60s living in the U.S. Sexually he was gay identified and was HIV negative, “out” and about equally likely as not to be in a long-term relationship with a man. Medically he was diagnosed with prostate cancer about 6 years previously and was successfully treated, about half the time with radical prostatectomy only, 18% with radiation and 28% with systemic treatment.

Sexual and urinary function following treatment are reported in detail in our companion article.[15] For context only 11.9% of participants described their sexual functioning after treatment as very good or excellent, 21.5% as good and 66.6% as fair to poor. Only 22.4% of patients reported erections sufficient for insertive anal sex. For receptive anal sex 33.8% of patients met criteria for anodyspareunia. For oral sex 67.4% reported at least occasional problems with urination during sex or at orgasm.

Only 17 participants (8.8%) reported that as part of their prostate cancer treatment someone took a sexual history, while 34 (17.6%) reported this history was taken “sort of/ maybe” and 134 (69.4%) confirmed that no history was taken. Eight respondents (4.1%) answered, “don’t remember.”

The potential problems that were discussed as part of treatment and experienced are listed in supplementary table 1 (http://jurology.com/). The 8 most common problems experienced by participants, ranked in terms of frequency, were loss of ejaculate (93.8%), erectile difficulties (89.6%), change in sense of orgasm (87.0%), loss of sexual confidence (76.7%), changes to the penis (65.8%), increased pain in receptive anal sex (64.8%), urinary problems not related to sex (64.2%) and urinary problems during sex or at orgasm (49.2%). Of these problems only loss of ejaculate (71.0%), erection difficulties (74.1%) and urinary problems not related to sex (74.6%) were reported as discussed before patients underwent treatment.

Potential rehabilitation options that were discussed as part of treatment and experienced are listed in supplementary table 3 (http://jurology.com/). Erectile enhancing drugs (84.5%), pelvic floor exercises for incontinence (68.9%), penile injections (56.5%) and vacuum pump (54.4%) were the rehabilitation options most discussed in treatment. Masturbation (92.7%), erectile enhancing drugs (86.5%), pornography to sustain interest (75.1%), pelvic

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floor exercises (72.5%) and vacuum pump (50.8%) were the options most commonly tried. Surgical implants (mean 4.12), pornography (3.82), referral to sexual counseling (3.50), use of dildos or butt plugs as anal dilators (3.38) and change in sex role (3.28) received above average satisfaction ratings, while Kegels (3.16), erectile enhancing medications (2.75) and vacuum pump (2.58) received average satisfaction ratings on a 5-point Likert-type scale.

For pelvic floor (Kegel) exercises we investigated how many exercises were prescribed. Of the participants 35 (18.1%) reported no number was specified, 39 (20.2%) stated the specialist stressed “as many as possible” and 27 (14.0%) did not recall. The remaining 37 respondents recalled recommendations from 0 or 1 to 250 daily (mean ± SD 45.7 ± 60.8, median 30). In estimating how many Kegels they actually did 46 participants (23.8%) did not remember and 53 (27.5%) were not assigned Kegels. For the remainder the estimated number performed ranged from 0 or 1 to 400 daily (mean ± SD 42.7 ± 68.5, median 20). Duration of performing Kegels was positively skewed, ranging from 0 to 24 months (mean ± SD 4.3 ± 4.0), with most respondents reporting doing Kegels for 2 (21 respondents, 15.6%), 3 (14 respondents, 10.4%) or 6 months (16 respondents, 11.9%).

Only 2 options were not commonly tried, ie surgical implants and sexual counseling (supplementary table 3, http://jurology.com/). Of the 15 participants (7.8%) who reported trying sexual counseling 14 reported individual counseling, 2 couple counseling, 2 group counseling and 2 an online or support group. Mean ± SD number of counseling sessions attended was 8.5 ± 7.6 (range 2 to 24).

Discussion

The main finding of this study is that there appears to be no standard of treatment, let alone standardized treatment, for sexual recovery from prostate cancer treatment for GBM. Despite sexual dysfunction being the major health sequela of prostate cancer treatment, less than 10% of respondents reported that anyone took their sexual history. (We caution that this may be an underestimate as those who received multiple treatments were instructed to answer about their most recent treatment or series of treatments). Only 3 of the 8 common problems experienced by most participants appear to have been discussed before or as part of treatment, leaving most patients to experience several problems without medical warning or guidance.

For participants who were offered rehabilitation choices 2 biomedical options (erectile enhancing drugs and penile injections) and 2 behavioral options (pelvic floor exercises and vacuum pump) appeared to be commonly discussed. When physicians discussed such options, most participants tried them, with the possible exception of penile injections.

GBM appear creative and willing to seek out treatment options and rehabilitation aids beyond what their clinicians recommend. A curious inverse relationship can be observed between what specialists discuss and participant satisfaction. Those rehabilitation options rated most highly by GBM in terms of satisfaction (ie surgical implants, pornography, sexual counseling, dildos and vasoconstrictive devices or “cock rings”) were those not commonly

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discussed, while the options commonly covered by clinicians (ie vacuum pump, erectile enhancing drugs and pelvic floor exercises) received only average satisfaction ratings.

Almost all participants reported masturbating to stimulate blood flow, most reported using pornography to sustain interest and many reported trying vasoconstrictive devices and dildos or butt plugs as anal dilators. They also experimented with changes in role in sex (ie going from being the insertive partner to receptive). As evidenced by the number of recommended pelvic floor exercises, what clinicians recommend appears highly idiosyncratic, with the range so wide it is impossible to assess whether exercises have any beneficial effect for GBM.

Clinicians cannot address the rehabilitation concerns of their patients if they do not monitor their sexual rehabilitation and/or are not aware of what patients attempt to address sexual challenges. To improve clinical practice and outcomes, we recommend that prostate cancer specialists consider adding 4 questions as a standard part of their initial assessment (supplementary Appendix, http://jurology.com/). Each of these questions is designed to yield information that may shape what cancer treatment choice is likely to have the least deleterious effects on the sexual lives of GBM and what rehabilitation options to discuss, while also addressing the ethical duty to avoid harm. For clinicians used to focusing on erectile rehabilitation for vaginal intercourse broadening how sex is defined may better address patient sexual health. Clinicians may wish to provide explicit permission to GBM to masturbate “to stimulate blood flow” and/or to use pornography “to sustain sexual interest” since these appear to be near universal practices.[16] As a participant remarked in the qualitative phase of this study, “[My surgeon] recommended I masturbate a lot, everyday if you can, which was wonderful. No one has ever given me permission to masturbate every day.”

These results also have implications for how prostate cancer specialists are trained and norms of practice. In our research and others participants expressed negative reactions to their treatment by specialists,[17–19] including anger when they felt lied to (meaning being given overly rosy predictions of outcomes) or when crucial information was omitted or discounted (eg about climacturia and changes to the shape and size of the penis).[17] Like their heterosexual counterparts,[20] some GBM who are prostate cancer survivors profoundly grieve the diagnosis and specific losses including ejaculate.[13,21–23] Those overseeing training programs for urologists, oncologists and others providing prostate cancer care need to ensure training in basic sexual counseling (eg PLISSIT model[16,24]) and in the culturally competent prostate cancer treatment of gay and bisexual men.

When interpreting the results of this study, a key limitation to consider is the challenge of retrospective recall. Concerns include that the average participant was diagnosed about 6 years previously, treatment is a stressful time for most men, and participants may not have heard everything the specialist said and/or may have simply forgotten what exactly was discussed. However, 1) on the qualitative questions participants were able to recall specific details, 2) options were provided for those who did not remember or preferred not to answer (and few men chose these options) and 3) sexual functioning is critical (and memorable) to many men and just because a population is older does not necessarily invalidate recall in that

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population. On balance we believe it is reasonable to use these methods to gain an initial picture of what survivors remember.

While geographically diverse, our study sample is fairly homogeneous, and we caution that the results might not generalize beyond a gay identified, white, North American sample. Also, the study used a convenience sample of men seeking online support services after treatment, which likely skews the sample toward men experiencing ongoing problems. Finally, a number of participants who were receiving hormone treatment described their sexual interest as reduced or eliminated and noted that many of the sexual questions were not applicable to them.

Despite these limitations, the study has strengths. As it is the largest study of GBM with prostate cancer conducted to date, the use of an online recruitment strategy appears successful. To overcome the danger of false responding, a rigorous, state of practice, cross-validation and deduplication protocol was used. This is the first study to focus on what rehabilitation options are offered and have been tried by GBM. We used a mixed methods approach, allowing in-depth qualitative interviews to inform our questions on treatment. We also added response options to distinguish inability to recall from preferring not to answer a question.

Our results fill an important gap in current knowledge. While the limited research conducted on GBM with prostate cancer has described the sexual challenges they experience, this study extends these findings by investigating what treatments GBM are offered and attempt.

Conclusions

This is the first known study to document the clinical problems GBM experience as part of prostate cancer treatment, what clinicians address and fail to address, and what rehabilitation methods GBM use in an attempt to recover from the urinary and sexual effects of treatment. The main finding is that rehabilitation appears so idiosyncratic that no clear practices or patterns could be discerned. The area of sexual rehabilitation in GBM lacks investigation of the problem, consensus on approach, and standards on how to assess and manage the effects of prostate cancer treatment. Having clinicians ask relevant sexual questions, educating patients to disclose their sexual orientation and behavior to specialists, developing training materials for prostate cancer specialists to provide competent care and advancing research to provide a much needed evidence base could significantly improve patient outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Abbreviations and Acronyms

GBM	gay and bisexual men
U.S.	United States

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