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The Sexual Functioning of Gay and Bisexual Men Following Prostate Cancer Treatment: Results from the Restore Study

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Abstract

Prostate cancer is the second most common cancer in gay, bisexual, and other men who have sex with men (GBM). Few studies have assessed the effects of treatment on GBM's sexual behavior. For an online survey, 193 gay and bisexual men with prostate cancer were recruited from the North American's largest online cancer support group. Sexual functioning was measured using the Expanded Prostate Cancer Index Composite (EPIC) and a tailored Gay Sexual Functioning Inventory (GSFI). GBM have worse EPIC urinary and hormonal function and worse hormonal bother, but better sexual function and bother scores than published norms. In the GSFI, two-thirds of participants described their sexual functioning, post-treatment, as fair to poor. Only 22% reported erections sufficient for insertive anal sex. For receptive anal sex, one-third met criteria for anodyspareunia. Over half reported urination problems during sex or at orgasm. Erectile difficulties were common, severe, and a reason cited for not using condoms. Three men HIV seroconverted post-prostate cancer treatment. Differences in function and bother scores were observed by type of treatment, age, race/ethnicity, sexual orientation, but not relationship status. Sexual functioning significantly predicted long-term mental and physical health. GBM scored significantly worse on mental health and better on physical health than published norms. Sexual recovery after prostate cancer treatment is problematic for most GBM. Research to develop more effective sexual recovery, tailored to the needs of GBM treated for prostate cancer, is needed. Six implications for clinicians treating GBM with prostate cancer are identified.

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Keywords

Prostate cancer; Gay and bisexual men; Sexual dysfunction

Introduction

Sexual function is an important component of health (Rosen, 2003) and predictor of quality of life (Beutel, Schumacher, Weidner, & Brahler, 2002; Laumann, Paik, & Rosen, 1999) for gay, bisexual, and other men who have sex with men (GBM) treated for prostate cancer (Rosser et al., 2016b). Most research on the effects of prostate cancer treatment has focused on heterosexual men, using instruments such as the Expanded Prostate Cancer Index (EPIC) (Wei, Dunn, Litwin, Sandler, & Sanda, 2000) to study the effects of treatment on sexual, urinary, bowel and hormonal function, and bother. Research indicates that type of prostate cancer treatment received affects especially sexual and urinary outcomes (Litwin et al., 2007; Penson et al., 2003), and that both urinary and sexual function and bother independently predict overall health-related quality of life (Penson et al., 2003).

Compared to heterosexual men, GBM's experience with prostate cancer and its impact on their health is poorly understood (Hoyt et al., 2017). Between 125,000 and 175,000 GBM in the U.S. are estimated to be living with a diagnosis of prostate cancer (Rosser et al., 2016c). This includes between 44,000 and 105,000 men in male couples. One-in-six GBM and one-in-three male couples will receive a diagnosis in their lifetime, making prostate cancer the most common invasive cancer in GBM, and male couples the most common relationship configuration to receive a prostate cancer diagnosis.

The 2011 Institute of Medicine (IOM) report on the Health of *Lesbian, Gay, Bisexual, and Transgender People* cites the lack of research into prostate cancer in GBM as an example of how disparities in health research negatively impact GBM's health (Institute of Medicine, 2011). Only seven quantitative studies have examined sexual functioning in GBM following prostate cancer treatment (Allensworth-Davies et al., 2015; Dowsett, Lyons, Duncan, & Wassersug, 2014; Hart, Coon, Kowalkowski, & Latini, 2011b; Lee, Breau, & Eapen, 2013; Motofei, Rowland, Popa, Kreienkamp, & Paunica, 2010; Ussher et al., 2016; Wassersug, Lyons, Duncan, Dowsett, & Pitts, 2013). Most report poorer quality of life outcomes for GBM, compared to either heterosexual men or published norms. These include lower scores on urinary and bowel domains (Allensworth-Davies, 2012; Hart et al., 2014; Lee et al., 2013) and worse hormonal symptoms (Hart et al., 2014). Sexually, GBM had improved erectile function (Hart et al., 2011b, 2014; Hart, Coon, Kowalkowski, & Latini, 2011a), but worse ejaculatory function (Lee et al., 2013; Ussher et al., 2016; Wassersug et al., 2013) and sexual bother (Lee et al., 2013) than published norms (for heterosexual men). The only treatment study found that GBM had worse sexual functioning following anti-androgen treatment than heterosexual men (Motofei et al., 2010).

While GBM and heterosexual men share many challenges in rehabilitation (Latini, Hart, Coon, & Knight, 2009), comparison of GBM and heterosexual men on standardized scales can only reveal part of the picture. Questions tailored for gay sex are needed to fully describe the effects of prostate cancer treatment on GBM's sexual functioning (Institute of

Medicine, 2011). A small qualitative literature has identified some specific challenges GBM face. These include the loss of ejaculate [considered more central in gay sex (Harris, 2005; Mitteldorf, 2005)]; stronger erections required for anal than vaginal sex (Gebert, 2014) (implying rehabilitation may be less successful for GBM); after prostatectomy, the loss of sexual pleasure in receptive sex (Santillo & Lowe, 2005; Smith, Filiault, Drummond, & Knappman, 2007); and after radiation treatment, persistent rectal irritation or pain sufficient to prevent receptive anal sex (Blank, 2005; Goldstone, 2005). Some changes in role in sex following treatment for prostate cancer have been reported (Hart et al., 2014); it is not clear how common this is for GBM. Arousal incontinence (i.e., the expression of urine during sexual arousal) and climacturia (i.e., the expression of urine at ejaculation) have also been mentioned anecdotally (Rosser et al., 2016a), but have not been investigated quantitatively. Finally, minority stress theory (Meyer, 2003) predicts that GBM should experience worse outcomes after prostate cancer treatment (Hoyt et al., 2017), especially given anecdotal reports of GBM experiencing treatment as heterocentric, heterosexist, or even discriminatory (Dowsett, 2018; Hoyt et al., 2017).

In preparation for this study, we conducted in-depth interviews, including 19 interviews with GBM who underwent radical prostatectomies (Rosser et al., 2016a, b) and 6 who received radiation treatment (West et al., 2018). All respondents reported significant sexual and/or urinary challenges following treatment. The primary purpose of this study was to quantify the incidence of sexual and urinary concerns in a cohort of GBM treated for prostate cancer and to study their effects on health-related quality of life. There were seven hypotheses:

1. Erectile difficulties would be common, severe, and negatively correlated with quality of life.
2. Erectile difficulties would be pervasive across different types of sexual behavior.
3. Condom use by GBM with prostate cancer in insertive anal sex would be low.
4. GBM who attempted to engage in receptive anal sex would report anodyspareunia (i.e., clinically significant pain) and anorgasmia (i.e., difficulty achieving orgasm).
5. Urinary problems during sex or at climax would be a common concern.
6. A common adaptation following prostate cancer treatment would be change in role in sex from being the insertive partner to being the receptive partner.
7. Quality of life outcomes would differ by key demographics (age, race/ethnicity, sexual orientation, relationship status, and treatment type).

Method

Participants

Recruitment for the *Restore* survey was conducted online at Malecare.org, a large North American cancer support group and advocacy organization. Annually, 800–1000 newly diagnosed GBM with prostate cancer seek support from *Malecare*. Participants were recruited through the organization's email listserv and banner advertisements: "Sexual

Effects of Prostate Cancer in Gay and Bisexual Men." By clicking on the advertisement, enrollees were transported to the study Web site where they completed an eligibility screener. To be eligible, a participant had to check that he was: (1) a gay, bisexual, or other man who has sex with men, (2) who had been treated for prostate cancer, and (3) residing in a US zip code or Canadian postal code. For consent, we adapted our published chunked online consent protocol (Rosser et al., 2009a). Enrollees reviewed and affirmed seven screens detailing study purpose, risks, benefits, and payment preference. A cross-validation and deduplication protocol (Grey et al., 2015) was used to flag and manually investigate suspect surveys. Data collection began October 21, 2015, and ended January 1, 2016 (72 days). Each participant received a $25 gift card as compensation.

Our primary recruitment strategy was a series of four emails sent to Malecare.org members at approximately 7–10-day intervals, supplemented by advertisements on Malecare.org. In total, we received 502 click throughs onto our welcome page. A total of 434 (86.5%) passed eligibility, and 417 (96.1%) consented to participate. Prior to analysis, 233 surveys were deemed invalid or duplicative (DeWitt et al., 2018). In addition, one incomplete survey was also removed, leaving 193 (99.5%) surveys deemed to be from unique, valid participants. In addition, 66 partners and caregivers completed a companion survey (data reported separately).

Measures

The survey questionnaire was in English and consisted of 15 sections with a total of about 150 questions. To minimize participant burden, skip and branch patterns were used to administer only those questions that were relevant to each participant.

Demographics, Sexual Characteristics, and Medical Information—Demographic questions (age, gender, race, ethnicity, and education) were adapted from the US Census. Sexual characteristic questions (identity, degree of outness, relationship status, and HIV status) were based on prior research (Rosser et al., 2009b, 2009c). Medical characteristic questions included prostate-specific antigen or PSA level at diagnosis (a biomarker used in prostate cancer screening) and Gleason score (a measure of tumor aggressiveness) and current prostate cancer status), the wording of which was taken from prior studies (Brimo et al., 2013; Latini et al., 2009; Wassersug, Westle, & Dowsett, 2016). Prostate cancer treatment was investigated by asking participants to check which of nine treatments they have undergone. At analysis, these were collapsed into three groups (surgery only, radiation only, and other/combination).

Disease Specific Quality of Life—The Expanded Prostate Cancer Index Composite (EPIC) is a comprehensive assessment of prostate cancer-related quality of life. This 50-item scale measured frequency and perceived bother in four domains (urinary, bowel, sexual, and hormonal). Each domain and subscale are scored from 0 to 100, with 100 indicating better health. A 26-item short form of the scale measures overall quality of life in five domains (urinary incontinence, urinary irritation or obstruction, sexual, bowel, and hormone). The EPIC-50 scale has acceptable scale and subscale reliability ($r \geq .80$) and internal consistency ($\alpha \geq 0.82$) (Hart et al., 2014; Wei et al., 2000).

Physical and Mental Quality of Life—The 12-item Short Form Survey (SF-12) is a generic measure of health functioning yielding two subscales (mental and physical functioning) which combine to estimate overall health-related quality of life. Each subscale is scored from 0 to 100, with 100 indicating better health. Two week test–retest reliability for the physical subscale was $r = .8$, and for the mental subscale $r = .76$ (Ware, Kosinski, & Keller, 1996).

Gay Sexual Functioning Inventory—Given the lack of scales to comprehensively assess sexual functioning in male–male sex, we developed 37 items to assess common sexual behaviors between men, including both insertive and receptive anal sex. Item development was guided by 39 in-depth interviews, including 19 with GBM treated with radical prostatectomy, 6 with radiation, and 6 with a combination or advanced treatment, 3 male partners, and 6 caregivers. The wording of questions and response options (using 5-item Likert type scales) is detailed in Supplemental Table 1.

Analysis

Univariable analyses were conducted to assess the crude associations between each EPIC domain and subscale and age, race, relationship status, sexual orientation, and treatment type. Categorical variables were analyzed using the chi-square test or Fisher exact test (where appropriate) for categorical variables and the *t* test for continuous variables. All reported *p* values were two-sided.

t-tests were used to compare EPIC-50 scores in this study to two comparator samples: one normative heterosexual sample (Wei et al., 2000) and a sample of gay and bisexual men (Hart et al., 2014). EPIC-26 scores were also compared to the normative heterosexual sample (Wei et al., 2000) using *t* tests.

Scores in each EPIC-50 domain and subdomain and SF-12 physical and mental domains were compared in bivariable analyses across categories of treatment, age, race/ethnicity, sexual orientation, and relationship status. Statistical significance in these analyses was assessed using ANOVA for categorical variables and *t*-tests for dichotomous variables.

Because scores on the four EPIC-50 domains are moderately correlated ($r = .25–.43$) (Wei et al., 2000), multivariate linear regression was used to assess the associations between each EPIC-50 domain and treatment regimen, race, age, relationship, and sexual identity. Because crude analyses revealed few differences between subscales and their associated domains, only the four main EPIC-50 domains (Urinary, Sexual, Bowel, and Hormone) were utilized in multivariate analysis. Multivariable logistic regression was used to evaluate the relationship presented in hypothesis 5. Data were analyzed using Stata version 12 (StataCorp, College Station, TX).

Results

The demographic, sexual, and medical characteristics of the participants are detailed in Table 1. To summarize, the typical participant in this study was a white, non-Hispanic, well-educated male, in his 60s, living in the U.S., gay-identified, HIV-negative, and “out.” He was

about equally likely to be in a long-term relationship with a man, or not. Geographically, the sample was diverse from 38 states and two Canadian provinces. Medically, the typical participant reported a prostate cancer diagnosis about 6 years ago with a Gleason score of 6–7 (indicating non-aggressive cancer). Just over half (99 or 51.3%) reported having received a radical prostatectomy only, 35 (18.1%) reported radiation treatment only, and 54 (28.0%) reported a combination of treatments including treatment for advanced prostate cancer. In total, 5 (2.8%) were on active surveillance or had cryotherapy.

Incidence of Sexual Behavior

During the preceding 3 months, of 190 responding participants, 67 (35.3%) participants reported no sexual partners, 58 (30.5%) had one partner, and 65 (34.2%) had between two and twenty partners (M = 1.92 partners, SD = 3.25). The results of the EPIC sexual subscale and GSFI questions are detailed in Supplemental Table 1. On the GSFI, questions 11–16 examined frequency of common sexual behaviors. Excluding those who marked "not applicable" and adjusted for "refuse to answer" on each item, 176 of 193 (91.2%) participants reported engaging in sexual behavior at least once during the last 4 weeks. In order of frequency, most reported masturbation (166 of 193; 86.5%), then receptive oral sex (99 of 181; 54.7%), insertive oral sex (76 of 182; 41.8%), receptive anal sex (55 of 150; 36.7%), insertive anal sex (37 of 147; 25.2%), and the least frequently reported behavior was vaginal sex (4 of 72; 5.6%).

Incidence of Sexual Problems

Hypothesis 1 predicted erectile difficulties would be common, severe, and negatively correlated with quality of life. Confirming this hypothesis, most (151 or 78.2%) rated their ability to get an erection as less than good, and 163 (84.9%) rated the quality of erections as less than firm enough for intercourse (see Supplemental Table 1). The correlation between the EPIC sexual subscale and the SF-12 physical components score was $r = .34$ ($p < .001$, df = 190) and the mental components score $r = .23$ ($p = .001$, df = 190). This confirmed sexual dysfunction predicted overall quality of life in this sample. Confirming hypothesis 2, only 24 of 107 (22.4%) evaluated their erectile functioning as adequate (i.e., good to excellent) for insertive anal sex and 4 of 19 (3.7%) as adequate for vaginal sex. In all, 99 of 115 (86.1%) reported at least some problems with getting an erection for insertive anal sex, including 80 of 115 (69.6%) who reported "often" to "always" having problems. For anorgasmia, 57 of 67 (85.1%) participants reported at least one recent incident of difficulty reaching orgasm in insertive anal sex.

Hypothesis 3 predicted condom use by GBM treated for prostate cancer would be low. This was also supported. Only 16 of 121 (8.2%) participants who engaged in insertive sex in the last 3 months reported using condoms: 8 with one male partner and 8 with two male partners. By contrast, 26 of 121 (21.5%) participants reported unprotected insertive anal sex: 16 with one partner, 7 with two, and 1 each with four, five, and twenty partners. For the 120 participants who answered the questions on receptive anal sex, 35 (29.2%) reported partners used condoms with them: 24 participants with one partner, 6 with two partners, and 1 each with three and four partners, 2 with five partners, and 1 with seven partners. However, 30 men reported unprotected receptive anal sex with one partner, 8 with two, and 1 with five.

Of the 62 participants who answered the GSFI questions on current insertive anal sex, 38 (61.3%) participants confirmed erection concerns as the reason for their not using condoms. Post-treatment for prostate cancer, three men reported being diagnosed with HIV and 8 with another (non-HIV) sexually transmitted infection.

Hypothesis 4 predicted GBM treated for prostate cancer who engaged in receptive anal sex would report anodyspareunia and anorgasmia concerns. This hypothesis was also supported. Overall, of participants not answering "not applicable" or "refuse to answer," 32 of 92 (34.8%) described their functioning in receptive anal sex as poor or fair, while 25 of 93 (26.9%) were "dissatisfied" or "very dissatisfied" with the quality of receptive sex. At least one painful occasion of receptive sex was acknowledged by 43 of 76 (56.6%) participants. Severe pain (i.e., anodyspareunia) was reported by 26 of 77 (33.8%) participants, and bleeding or irritation by 23 of 76 (30.3%) participants during the preceding 4 weeks. In comparing current experience of pain with prior experience, 25 of 68 (36.8%) participants reported receptive anal sex as "very painful," "painful," or as "having no feeling" currently, compared with 18 of 128 (14.1%) in the year prior to treatment ($p = .021$). Only 4 of 158 (2.5%) participants stated they would expect to experience some pain, ideally ($p = .042$). Supporting hypothesis 5, just over half (99 or 51.6%) of participants reported some involuntary urination during sex or at orgasm.

For hypothesis 6, three GSFI questions examined change in role in sex by comparing a participant's current role in sex with that in the year before treatment and what they would like, ideally. While 178 of 193 (92.2%) participants were able to state a preferred role in sex (ideally), and 156 (80.8%) reported a role in sex in the year prior to treatment, only 85 (44.5%) reported a "current" role in sex. Because of this large difference in denominators, formal statistical testing was not appropriate to compare change in role. Currently, only 16 (8.2%) indicated they were an exclusive or versatile "top" (i.e., the insertive partner in anal sex), compared with 65 of 156 (41.7%) participants who identified as tops in the year prior to treatment, and 45 of 178 (25.3%) who would so identify, ideally. For versatile to exclusive "bottoms" (i.e., receptive partners in anal sex), currently, 55 out of 85 (64.7%) identified as such. This is compared with 57 out of 156 (36.5%) in the year prior to treatment and 55 out of 178 (30.8%), ideally. Currently, 9 (4.7%) identified as "versatile" (meaning they engage in both roles), compared to 34 (17.6%) in the year prior to treatment, and 78 (40.4%), ideally.

Prostate Cancer Treatment-Specific Outcomes

Comparison of EPIC scores with published norms for the EPIC 50 (Wei et al., 2000) identified our sample as having significantly worse urinary function, better sexual function, and bother, but worse hormone function and bother than the (heterosexual) normative comparison group (see Table 2). These results were replicated using the EPIC-26 norms as well where the GBM scored better also on bowel outcomes.

Overall Quality of Life

GBM participants scored significantly worse on overall mental health (MGBM = 46.0; $SE_{GBM} = 0.8$; $M_{HET} = 58.0$, $SE_{HET} = 0.7$; $t = -13.8$; $p < .0001$, df = 358), but better on

overall physical health (M_{GBM} = 52.5; SE_{GBM} = 0.6; M_{HET} = 48.4, SE_{HET} = 0.8; t = 4.1; p < .0001, df = 358) compared to published results for other prostate cancer survivors (Choi et al., 2016).

Differences by Age, Race/Ethnicity, Sexual Orientation, Relationship Status, and Treatment on Key Outcomes

Supporting Hypothesis 7, there was a consistent pattern of differences observed across key demographics (see Supplemental Table 2). Younger GBM had higher scores on EPIC measures than older men, including significantly better urinary subtotal and bother scores, and sexual overall, bother, and function scores than older men. White, non-Hispanic men had higher scores on all EPIC scales than GBM of Color, but only the hormonal subscale, function, and bother scores reached statistical significance. Gay-identified men tended to score better than bisexual men, including statistically significantly better outcomes on the bowel subscale, function, and bother scores. However, men in relationships did not differ from single men on any of the domains (data not shown). The most striking differences were observed across treatment type. The surgery-only group had significantly better scores on ten of the twelve outcomes than the combination group, while the radiation group also had significantly better scores on three outcomes (urinary function, sexual subscale, and function) than the combination group. Between the surgery and radiation groups, the surgery-only group scored worse on urinary function, but better on bowel subscale and bowel bother than the radiation group.

In multivariate analyses controlling for all other variables, other/combination treatment was associated with worse sexual, bowel, and hormone EPIC-50 scores than surgery alone, but no difference in urinary scores. Radiation was associated with worse bowel scores than surgery alone, but no difference in urinary, sexual, or hormone scores. There were no differences in adjusted scores in any domain for race or relationship status. Older age was associated with worse sexual scores, but no difference in urinary, bowel, or hormone scores. Participants identifying as gay/homosexual had better bowel outcomes than those identifying as bisexual/other, but no difference in urinary, sexual, and hormone scores (Table 3).

On the SF-12 overall quality of life measure, older GBM had significantly better mental health scores, but poorer physical health scores than younger GBM (see Supplemental Table 2). GBM who received surgery had significantly better mental health scores than GBM in combination treatment. There were no other significant differences.

Differences by Age, Race/Ethnicity, Sexual Orientation, Relationship Status, and Treatment on Condom Use, Urination During Sex/Climacturia, and Receptive Anal Sex

There were no significant differences found by age, race/ethnicity, sexual orientation, or relationship status on condom use, urination during sex, or receptive anal sex. For condom use in insertive anal sex, the surgery-only group (M_{sur} = 0.28, SE_{sur} = 0.08, n = 28) reported significantly less frequent condom use than those who received combination therapy M_{com} = 0.65, SE_{com} = 0.09, n = 21; $F(2, 58)$ = 5.01; p < .01) with the radiation group falling in between (M_{rad} = 0.57, SE_{sur} = 0.13, n = 11). For involuntary urination during sex or at orgasm, the surgery group (M_{sur} = 0.49, SE_{sur} = 0.04, n = 90) scored significantly

worse on this item than the combination treatment group (M_{com} = 0.37, SE_{com} = 0.05, n = 47), who in turn scored significantly worse than the radiation group (M_{rad} = 0.01, SE_{rad} = 0.07, n = 23; $F(2, 158) = 18.1$; $p < .0001$). However, treatment did not significantly distinguish problems in receptive anal sex (on any of the three questions). There were no other significant differences across demographics.

Discussion

We highlight nine key findings in this study. First, against the stereotype of older men being no longer sexual, almost all GBM treated for prostate cancer reported some recent sexual activity, either alone or with a partner. Second, most rated the quality of their sexual functioning as highly problematic, indicating that sexual recovery of GBM after prostate cancer is possible, but very challenging. Third, this is the first study to quantify treatment effects on receptive anal sex and urination during sex or at orgasm. Both appear to be common challenges, with the former being particularly problematic for GBM who received radiation and the latter problematic only for those who received surgery [while studies of painful receptive anal sex are rare, the 14 percent of participants who described receptive sex as “very painful,” “painful,” or “no feeling” in the year prior to treatment closely matches prior investigations of painful receptive sex in GBM (Damon & Rosser, 2005; Rosser, Metz, Bockting, & Buroker, 1997; Rosser, Short, Thurmes, & Coleman, 1998)]. Fourth, HIV and STI risk following treatment is a key concern particularly for those who received surgery. Very few GBM who engaged in insertive anal sex reported using condoms, with most citing erection difficulties as the underlying reason for non-condom use. This finding is highly concerning, especially given that three men, who had remained HIV-negative throughout the AIDS epidemic, reported being diagnosed with HIV since their treatment for prostate cancer, and eight reported a (non-HIV) STI. Fifth, an unexpected result was the loss of role-in-sex identity. This suggests that rather than tops becoming bottoms, the more common outcome is a loss of identity. Sixth, confirming its importance in cancer survivorship, sexual function was associated with better mental and physical quality of life in GBM. Seventh, evidence of health disparities by sexual orientation was found. Compared to the published norms for heterosexual prostate cancer survivors, GBM had worse urinary function, worse hormonal function, and bother, but better sexual function and less bother than published norms for other prostate cancer survivors. Eighth, in the first study large enough to test for demographic differences between GBM, older men, GBM of Color, non-gay-identified GBM, and men who received combination or advanced treatment had poorer outcomes. Ninth, treatment differences appeared the key variable predicting poorer outcomes across multiple scales.

The overall picture that emerges is that sexual recovery is a major problem for GBM, post-treatment for prostate cancer. With only 11.9% of participants describing their sexual functioning as good or excellent, treatment is failing almost nine out of every ten participants in this study. Given the association between sexual function and overall quality of life (especially mental health), future research needs to focus on improving sexual outcomes for GBM.

Replicating Hart et al.'s (2014) findings in GBM, the sexual bother scores of GBM were significantly better than published norms. While heterosexual survivors' sexual functioning may be worse than GBM's, a simpler explanation is that the norms for the EPIC sexual bother scale are problematic. Both the EPIC-50 and EPIC-26 were normed before the FDA approved the first oral PDE-5 inhibiting drugs for the treatment of erectile dysfunction, and 43% of the normative sample appear to not have received treatment (Wei et al., 2000). At least one recent study of heterosexual prostate cancer survivors also reports better overall sexual function scores than the published norms (Thomas, Wootten, Robinson, Law, & McKenzie, 2018). We caution researchers that this scale may need to be re-normed. Future research in GBM prostate cancer disparities should directly compare GBM and heterosexual prostate cancer survivors and adjust for those variables found significant after multivariate analysis (i.e., treatment, age, and sexual orientation).

This is the first sample of GBM prostate cancer survivors large enough to examine outcome differences by key demographics. The findings that older men and GBM of color tend to fare worse mirror similar findings in heterosexual survivors. That gay-identified GBM fare better than their bisexual counterparts adds to a growing literature identifying bisexual identity as a health disparity, compared to exclusively gay or exclusively heterosexual-identified men (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013). Friedman et al. (2014) attribute disparities experienced by bisexually identified men to double discrimination experienced by bisexual identified individuals.

We highlight six implications for clinicians. First, only two-thirds of participants were out to their prostate cancer specialists, and cancer registries in North America do not routinely track sexual orientation. Asking about sexual orientation could improve clinical practice. Second, given that almost all GBM were sexual, post-treatment, clinicians should assume their GBM patients want to be sexual as well. Third, the sexual effects of treatment are much broader than only erectile dysfunction. With GBM patients, clinicians should discuss effects on receptive anal sex, urination in sex, and change in role in sex (i.e., from receptive to insertive) since all three appear common concerns. We caution that relying only on the two most commonly used instruments in clinical treatment (EPIC and the Sexual Health Index for Men or SHIM) will miss these behaviors. Fourth, clinicians should caution GBM against expecting too rosy a picture of sex, post-treatment, given the substantial problems reported. Patients may be overly optimistic about their chances of sexual recovery even when fully forewarned (Wittmann et al., 2011). Fifth, given that GBM are a high-risk population for HIV and other STIs, we highlight a concern regarding patients becoming HIV/STI infected because of treatment-induced erectile dysfunction. The danger of erectile difficulties leading to HIV/STI transmission either through change in role in sex or non-condom use needs to be discussed with patients. Such discussions could highlight alternatives to condoms, such as pre-exposure prophylaxis (PrEP) and referral to a PrEP provider for HIV-negative patients, and review of antiretroviral medication adherence for HIV-positive ones. While these recommendations emerge from the experience of GBM, they may well apply to many high-risk heterosexual men as well.

There are several limitations to note when interpreting these results. First, this survey study used a convenience sample of GBM in North America recruited from an online social

support Web site. Such sites may over-recruit men experiencing sexual difficulties which could inflate estimates. Given the sample demographics, we caution against generalizing to GBM in other countries, to GBM of Color, and to GBM who are not online. Second, this study asks novel questions in several areas, including effects on masturbation, urination in sex, receptive anal sex, and condom use. Replication studies will be needed to determine the reliability of results. Third, sexual behavior is an area of socially sensitive research where respondents may be embarrassed to admit to engaging in stigmatized behavior and/or to inadequate sexual functioning. While online survey research appears superior to other methods in limiting this bias (Turner et al., 1998), the results may underestimate the true extent of the problem. In a cross-sectional survey design, causality cannot be inferred. While it is reasonable to posit that the sexual difficulties lead to poorer quality of life, the reverse could also be true. Similarly, it is reasonable, given the literature, to assume that the sexual difficulties reported in this paper were caused by prostate cancer treatment. However, other factors such as medications, other health challenges, and aging likely also contribute to impaired functioning. Fourth, appropriate to an under-researched area of study, a large number of statistical tests were conducted. Some significant findings could be due to chance.

Keeping these limitations in mind, this study also has several strengths. This is the largest study of GBM prostate cancer survivors conducted to date and the first with adequate sample size to explore differences by key demographics. This is also the first study to quantify the effects of prostate cancer treatment across the range of common gay sexual behaviors. It is also the first to document problems of urination in sex, anodyspareunia, and HIV/STI risk through non-condom use in GBM prostate cancer survivors. The recruitment statistics show an unusually high proportion of GBM (96.1% of initiated, non-duplicative surveys) consenting to participate for an online survey study and an almost perfect completion rate (99.5% of initiated, non-duplicative surveys). At the end of the survey, many participants provided comments either highlighting the urgent need for research in this area or thanking us for researching an area so important to them. Based on this feedback, it is reasonable to conclude the high consent and completion rates are some combination of strong participant commitment, the novel area of study, a benefit of recruiting from an online community addressing these concerns, and other factors.

In online distance studies and particularly those which offer compensation, a major threat to validity is the risk either of fake respondents attempting to enter such studies and/or participants completing the same survey multiple times (Grey et al., 2015). Both can skew results (Ross, Rosser, Coleman, & Mazin, 2006). We employed a strong deduplication and cross-validation protocol to detect and minimize this threat and have published it to encourage others to do the same (DeWitt et al., 2018). A large comprehensive survey was employed, examining not just sexual behavior outcomes themselves (reported here), but also the sexual recovery treatments tried (Rosser et al., 2018b) and a needs assessment published elsewhere (Rosser et al., 2018a). The combined use of the EPIC, GSFI, and the SF-12 has enabled us to go in depth and detail the effect of treatment on GBM's sexual lives, using validated scales where appropriate, supplemented with gay specific questions.

In terms of future research, this study confirms that the diversity of sexual behavior in GBM poses additional challenges for health disparities research. On EPIC, our results largely

replicate the findings of Hart et al., (2014). However, more research to directly compare GBM and heterosexual prostate cancers survivors is needed. Two studies using comparative designs have recently been published, but both have limitations. The Wassersug et al. (2013) study was sociologic in focus, so did not use standardized scales. Ussher et al. (2016) did use standardized scales, but used different recruitment methods to attain their GBM and heterosexual samples. (Both studies also recruited globally which introduces additional variance, and they did not validate their online samples.) To confirm sexual minority prostate cancer health disparities, a controlled study is needed where GBM and heterosexual prostate cancer survivors are recruited using identical methods, adequately validated, and adjusted to control for different treatment choices, time since treatment, and key demographics.

Conclusions

While GBM had better scores on sexual function than published norms, sexual functioning remained problematic for most GBM following prostate cancer treatment. Major challenges identified included erectile difficulties and condom use in insertive anal sex, involuntary urination and climacturia in oral sex, and anodyspareunia and anorgasmia in receptive sex. Given these challenges, research to advance tailored rehabilitation programs for GBM in prostate cancer treatment is warranted.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic, sexual, and medical characteristics of study participants (*N* = 193 GBM treated for prostate cancer)

	N	%
Demographics		
Nationality		
Canada	10	5.2
USA	183	94.8
Gender		
Male	192	99.5
Transgender, male to female	1	0.5
Age		
40–49	9	4.7
50–59	55	28.5
60–69	82	42.5
70–79	43	22.3
80–89	4	2.1
Race		
White	172	89.1
Black/African American	9	4.7
Asian American	4	2.1
American Indian/Alaska Native American	2	1.0
Native Hawaiian/Pacific Islander	1	0.5
Other	5	2.6
Ethnicity		
No hispanic origin	186	96.4
Hispanic	6	3.1
Education level		
Less than high school	1	0.5
High School of GED	6	3.1
Some college of associate’s degree	37	19.2
Bachelor’s degree	69	35.8

	N	%
Graduate degree	80	41.5
Sexual characteristics		
Sexual orientation identity		
Gay/homosexual	175	90.7
Bisexual, other	18	9.3
Outness of sexual orientation		
Not out at all	4	2.1
Out to a few people	30	15.5
Out to about half the people I know	9	4.7
Out to most people	33	17.1
Out to all or almost all people I know	117	60.6
Current relationship status (to a man)		
Single	58	30.1
Dating	13	6.7
Married or in long-term relationship	103	53.4
Widowed, divorced, no longer in relationship	14	7.3
Medical characteristics		
HIV status		
HIV-negative	168	87.0
HIV-unsure	1	0.5
HIV-positive (infected before treatment for prostate cancer)	21	10.9
HIV-positive (infected since treatment for prostate cancer)	3	1.6
Gleason score at diagnosis		
2–5	30	12.0
6	48	24.9
7	61	31.6
8	16	8.3
9	11	5.7
10	2	1.0
Don't know/don't remember	31	16.1
Treatment[b]		

	N	%
Surgery (e.g., radical prostatectomy)	132	68.4
External radiation therapy (XRT electron beam radiation)	70	36.3
Brachytherapy (radiation using seed implant therapy)	21	10.9
Cryotherapy (liquid argon gas into the prostate)	4	2.1
Medical castration (drugs to stop hormone production)	38	19.7
Surgical castration (removal of the testes)	0	0.0
Diet and/or alternative therapy (e.g., selenium, vitamin E)	22	11.4
Watchful surveillance (wait and see)	36	18.7
Where treated		
Canada	9	4.7
Midwest USA	35	18.1
Northeast USA	53	27.5
Southern USA	33	1.1
West Coast	62	32.1
Outside Canada/USA	1	0.5
Current status (check all that apply)		
Still in treatment	34	17.6
Finished treatment and cancer is undetectable	134	69.4
Still have detectable levels of prostate cancer	23	11.9
My prostate cancer has progressed	12	6.2
Outness re: Having Prostate Cancer		
Not out at all	1	0.5
Out to a few people	30	15.5
Out to about half the people I know	25	13.0
Out to most people	43	22.3
Out to all or almost all people I know	93	48.2
Outness as gay to Cancer specialist		
Not out at all	40	20.7
"Semi-out" to at least one prostate cancer specialist	21	10.9
Out to at least one prostate cancer specialist	132	68.4
Clinical characteristics at diagnosis	*n*[a]	Mean (SD)

	N	%
Time since diagnosis (years)	186	5.7 (4.5)
PSA level	149	7.6 (6.5)
Gleason score	161	6.5 (1.5)

[a] Excludes “don’t remember/don’t know” and “refuse to answer”

[b] Treatment categories are as worded on the survey. Due to an oversight, active surveillance and watchful waiting were presented as one term, “watchful surveillance”

Table 2

Comparison of scores between current sample and published norms for Expanded Prostate Cancer Index Composite (EPIC-50 and EPIC-26)

	Current Sample		Comparator 1: normative heterosexual (Wei et al. 2000)				Comparator 2[a]: gay and bisexual men (2014)			
	193 GBM PCa survivors		*N* = 252 prostate cancer patients				*N* = 90 GBM PCa survivors			
	N	**M (SE)**	***N***	**M (SE)**	***t*-score**	***p***	***N***	**M (SE)**	***t*-score**	***p***
a. Comparisons using EPIC-50 norms										
EPIC urinary										
Function	192	81.4 (1.4)	252	86.5 (1.0)	− 2.99	.0029	90	67.2 (2.8)	5.07	< .0001
Bother	193	74.5 (1.5)	252	75.8 (1.3)	− 0.65	.5152	90	68.9 (3.1)	1.85	.0652
EPIC sexual										
Function	189	40.5 (1.7)	252	29.5 (1.5)	4.84	<.0001	89	38.7 (2.6)	0.57	.5628
Bother	191	55.0 (1.8)	252	41.1 (1.9)	5.22	<.0001	88	40.1 (3.6)	4.19	< .0001
EPIC bowel										
Function	192	89.0 (0.9)	252	87.9 (0.9)	0.86	.3860	90	77.6 (2.2)	5.75	< .0001
Bother	192	84.5 (1.2)		85.3 (1.2)	− 0.44	.6554	90	77.5 (3.0)	2.62	.0092
EPIC hormone										
Function	192	79.3 (1.3)	252	84.0 (1.0)	− 2.94	.0035	85	73.5 (2.4)	2.25	.0249
Bother	191	82.1 (1.3)	252	88.7 (0.9)	− 4.44	< .0001	90	52.4 (2.1)	12.54	< .0001

b. EPIC-26 results	**Current sample**		**Comparator 1: Normative heterosexual (Motofei et al. 2010)**			
	N	**M (SE)**	***N***	**M (SE)**	***t*-score**	***p***
b. Comparisons using EPIC-26 norms						
EPIC urinary						
Incontinence	191	71.7 (2.1)	252	83.2 (0.7)	5.8	.0001
Irritation or obstruction	192	82.4 (1.3)	252	80.5 (0.7)	1.4	.17
EPIC sexual	186	54.0 (1.7)	252	34.4 (0.9)	10.9	.0001
EPIC bowel	191	88.7 (1.1)	252	85.0 (0.6)	3.13	.002
EPIC hormone	191	80.1 (1.4)	252	87.1 (0.5)	5.20	.0001

Quality of life scores are from the EPIC-50 scaled 0–100 with higher scores reflecting better health

Comparator 2 reproduces the results of Hart et al., the only other study to compare GBM prostate cancer survivors to the EPIC-50 norms

Table 3

Multivariate analysis showing risk differences for quality of life scores adjusting for other covariates (N = 191 GBM prostate cancer survivors)

Variable	Category	Risk difference			
		Urinary β (SE)	Sexual β (SE)	Bowel β (SE)	Hormone β (SE)
Treatment	Surgery only	0.00 (ref)	0.00 (ref)	0.00 (ref)	0.00 (ref)
	Radiation only	3.24 (3.73)	0.03 (4.17)	− 7.21 (2.53)[a]	− 4.83 (3.45)
	Other/combination	− 4.20 (3.03)	− 12.61 (3.39)[a]	− 9.28 (2.05)[a]	− 11.21 (2.81)[a]
Race	White/non-hispanic	0.00 (ref)	0.00 (ref)	0.00 (ref)	0.00 (ref)
	Other race/ethnicity	− 2.62 (4.05)	− 3.41 (4.53)	− 1.81 (2.75)	− 6.89 (3.75)
Age	65 and younger	0.00 (ref)	0.00 (ref)	0.00 (ref)	0.00 (ref)
	Older than 65	− 6.11 (2.76)	− 11.36 (3.09)[a]	− 1.18 (1.87)	− 1.64 (2.56)
Relationship status	Single	0.00 (ref)	0.00 (ref)	0.00 (ref)	0.00 (ref)
	Dating	0.25 (5.64)	8.05 (6.32)	− 3.72 (3.83)	6.89 (5.23)
	Married/partnered	0.62 (3.03)	0.97 (3.40)	− 1.57 (2.06)	− 1.64 (2.56)
	Widowed/divorced	6.88 (5.7)	4.13 (6.34)	2.11 (3.84)	− 4.84 (5.25)
	Refuse to answer	− 0.17 (8.76)	− 9.17 (9.80)	4.71 (5.94)	2.76 (8.11)
Sexual orientation	Gay/homosexual	0.00 (ref)	0.00 (ref)	0.00 (ref)	0.00 (ref)
	Bisexual/other	3.30 (4.83)	− 1.30 (5.42)	9.74 (3.28)[a]	− 2.24 (4.48)

Quality of life scores are from the EPIC-50 scaled 0–100 with positive numbers reflecting better health scores. So, a 10-point risk difference reflects 10% better health

[a]Denotes p value < .005