

## CHAPTER 1

# Understanding Prostate Cancer in Gay, Bisexual, and Other Men Who Have Sex with Men and Transgender Women

## A Review of the Literature

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### CHAPTER SUMMARY

Prostate cancer in sexual and gender minorities is an emerging medical and public health concern. The purpose of this review is to summarize the state of the science on prostate cancer in gay, bisexual, and other men who have sex with men (GBM) and transgender women (TGW). We undertook a literature review of all publications on this topic through February 2017. With 88 unique papers (83 on prostate cancer in GBM and 5 case reports of prostate cancer in TGW), a small but robust literature has emerged. The first half of this review critiques the literature to date, identifying gaps in approaches to study. The second half summarizes the key findings in eleven areas. In light of this admittedly limited literature, GBM appear to be screened for prostate cancer less than other men, but they are diagnosed with prostate cancer at about the same rate. Compared to other men, GBM have poorer urinary, bowel, and overall quality-of-life outcomes but better sexual outcomes after treatment; all these findings need more research. Prostate cancer in TGW remains rare and underresearched, as the literature is limited to single-case clinical reports.

### KEY TERMS

bisexual, cancer, gay, prostate, sexual rehabilitation

## INTRODUCTION

Research on prostate cancer in sexual and gender minorities is an emerging field of study. In the United States, improving the health of lesbian, gay, bisexual, and transgender (LGBT) individuals is a Healthy People 2020 goal.<sup>1</sup> The failure of science to conduct studies specifically on LGBT populations, however, results in health disparities in some diseases, including prostate cancer.<sup>2</sup> Clearly, clinicians cannot practice evidence-informed medicine without studies being conducted to inform their practice.

The purpose of this review is to provide an informed overview of the state of the science regarding prostate cancer in gay, bisexual, and other men who have sex with men (GBM) and transgender women (TGW). Some of the studies reviewed in this chapter are described in more detail in subsequent chapters in this book. This review contextualizes all the studies' findings in relation to one another, identifying areas for future research.

In February 2017 we performed a systematic literature search and review.<sup>3</sup> Database searching was conducted using MEDLINE via Ovid and PubMed, EMBASE, PsycINFO, and Social Work Abstracts. The search yielded 52 unique citations focused on prostate cancer in GBM or TGW. A supplemental search of bibliographies added 39 references. Excluding three duplicate citations, the complete search yielded a total of 88 original works. Of these, 83 focused on prostate cancer in GBM and 5 on prostate cancer in TGW. Allowing for multiple papers from the same study, there were 28 case studies (table 1.1), 8 qualitative studies (table 1.2), and 8 quantitative studies (table 1.3).

## THE KEY QUESTIONS

The main results of the literature to date have addressed the following eleven key questions.

**1. How many GBM are living with a prostate cancer diagnosis?** No precise estimate of the number of GBM and TGW living with prostate cancer exists. Prostate cancer is the second-most common cancer among men; 2,795,592 men in the United States were living with prostate cancer in 2012.<sup>4</sup> The Centers for Disease Control and Prevention (CDC) estimates that 3.5–4.4% of U.S. men have had sex with a man in the last five years,<sup>5</sup> of whom 40–60% are in sexual relationships.<sup>6,7</sup> By extrapolation, between 97,845 and 123,006 GBM are living with a

**TABLE 1.1**

Literature on Prostate Cancer in Gay and Bisexual Men and Transgender Persons (*N* = 88 citations)

Number and Type of Contribution	Operational Definition	Citations
Works Containing Original Data or Original Scientific Contributions		
Case Report ( <i>N</i> = 28)	<i>N</i> ≤ 5 participants on GBM	34, 38, 48, 52-54, 61, 63, 67, 72-86
	<i>N</i> ≤ 5 participants on TGW	9, 87-90
Qualitative Study Report ( <i>N</i> = 11)	Study with > 5 participants (to inform saturation) using qualitative analyses	28, 29, 42-44, 62, 68, 91-96
Quantitative Study Report ( <i>N</i> = 19)	a. Surveillance: study analyzing secondary data from large data set	10, 14, 20, 97, 98
	b. Observational: study with > 5 participants generating original data using quantitative methods and/or analyses	25-27, 30, 59, 99-105
	c. Treatment: study with > 5 participants where the focus is on testing a new treatment or rehabilitation	106
Works Not Reporting Original Data or Formal Studies		
Review ( <i>N</i> = 9)	Paper reporting findings from multiple studies to review the literature	8, 11, 60, 107-112
Clinical Observation and/or Educational Articles ( <i>N</i> = 13)	Focus is on treatment, rehabilitation, patient education, or lessons learned at a broad level without detailed description of participants, studies, or results	35-37, 52-54, 56, 63, 113-123
Commentary ( <i>N</i> = 5)	Introduces other papers or topics or comments on other studies/works (including book reviews)	55, 124-127
Other ( <i>N</i> = 2)	Category of last resort for citations not fitting into the above; includes books	128, 129

diagnosis of prostate cancer, including 39,138 to 73,804 men in male couples.<sup>8</sup> One in six GBM and one in three male couples will receive a diagnosis in their lifetimes. It is impossible to estimate the prevalence of prostate cancer among TGW. Because the development of prostate cancer after orchidectomy is rare,<sup>9</sup> the number of TGW with prostate cancer in a country is probably a function of the availability of gender-reassignment surgery and hormone therapy.

**2. Do GBM engage in prostate cancer screening at different rates from other men?** In the only study of PSA screening ( $N = 19,410$  men in the California Health Interview Survey), GBM had lower odds of having an up-to-date prostate-specific antigen test than did heterosexual men ( $OR = 0.61$ ;  $CI = 0.42, 0.89$ ), and bivariate analyses showed African American GBM as having lower rates than either heterosexual African American men or white GBM.<sup>10</sup> More research is needed.

**3. Are GBM at disproportionately greater risk for prostate cancer than other men?** Santillo and Lowe<sup>11</sup> identify six “lifestyle co-factors” that theoretically could increase the risk of prostate cancer in GBM: use of testosterone supplements and anabolic steroids, use of finasteride (Propecia) for hair loss, HIV status and antiretroviral (ARV) treatment, a fatty diet, the effects of anal sex on prostate-specific antigen (PSA) testing, and poor doctor-patient communication.<sup>11</sup> Because GBM are disproportionately at greater risk for HIV and other sexually transmitted infections (STI), comparative studies of prostate cancer incidence by orientation need to control for HIV and STI history.<sup>12</sup>

Three epidemiologic case-control studies inform this question, and their conclusions differ. One study comparing men with prostate cancer with a control group of men matched on age and race found that members of the prostate cancer group were more likely to have a history of STIs, and more likely to report homosexual partners, than the control group.<sup>13</sup> A second study determined that prostate cancer risk increased with lifetime numbers of female partners and with a history of gonorrhea; however, orientation identity, anal sex, and a history of male partners were not associated with increased risk.<sup>14</sup> A third study found that men with 20 or more lifetime female sexual partners were at lower risk of prostate cancer than men with fewer female partners, whereas men with 20 or more lifetime male partners were at a slightly higher risk. Though sex with 20 or more men was associated with elevated risk, neither history of STIs nor sexual orientation identity as gay or bisexual was significantly associated with risk.<sup>15</sup>

**4. Does an HIV diagnosis or treatment change GBM’s risk for prostate cancer?** Yes. Though early studies suggested an increased risk of prostate cancer among HIV-positive than among HIV-negative men,<sup>16, 17</sup> studies in the era of ARV treatment show an inverse association.<sup>18–20</sup> A cohort study of men with clinical AIDS found no difference in prostate cancer

**TABLE 1.2**

Qualitative Studies with  $N > 5$  Participants ( $N = 8$  Studies)

	<b>Study Logistics</b>	<b>Methods (Design, Recruitment, Participants, Procedures)</b>	<b>Key Results</b>
1	<p><b>PI:</b> Fergus  <b>Year of study:</b> 2002  <b>Site:</b> Toronto, Canada  <b>Language:</b> English  <b>Funding:</b> Canadian Institutes of Health Research (CIHR)</p>	<p><b>Design:</b> In-person, in-depth interviews  <b>Participants:</b> <math>N = 18</math> participants, including 14 heterosexual (including 4 Afro-Canadian) and 4 homosexual (all Euro-Canadian)  <b>Procedures:</b> Sample recruited from local prostate cancer support group, through advertisements in the gay and black media, GP referral, and personal contacts  <b>Inclusion/exclusion criteria:</b> Must have lived with prostate cancer diagnosis for minimum of one year</p>	<p><b>Sexual effects:</b> Using grounded theory, one core category emerged (labeled "preserving manhood") with 5 themes: (1) enhancing the odds; (2) disrupting a core performance; (3) baring an invisible stigma; (4) effortful-mechanical sex; and (5) working around the loss. No formal comparison of heterosexual versus gay survivors seems to have been performed; authors concluded that the commonalities, not differences, were striking. Authors note that all the heterosexual men were partnered, whereas only 1 of the 4 gay men were, and that black heterosexual men were particularly concerned about loss of sexual ability and perhaps less willing to participate in treatment.<sup>44</sup></p>
2	<p><b>PI:</b> Asencio  <b>Year of study:</b> Not specified (pre-2009)  <b>Site:</b> Hartford, Conn.  <b>Language:</b> English and Spanish  <b>Funding:</b> Private foundation and internal</p>	<p><b>Design:</b> 5 focus groups (3 mixed, 1 African American, and 1 bilingual in Spanish)  <b>Participants:</b> 36 gay men (not prostate cancer survivors)  <b>Procedures:</b> Flyers in community organizations and at Gay Pride  <b>Inclusion/exclusion criteria:</b> No requirement to have prostate cancer</p>	<p><b>Sexual effects:</b> Gay men have little understanding of the prostate and sexual challenges of treatment. Some hold beliefs that rough sex can cause (or prevent) prostate cancer. In Latino and black gay men, machismo and medical skepticism may prevent screening, respectively. Gay men overstressed prostate cancer being fatal. About half would seek treatment and half stated they would avoid treatment to preserve sexual functioning; older white men preferred treatment over function. Black and Latinos described more pressure to preserve sexual function.<sup>91</sup></p>
3	<p><b>PIs:</b> Dowsett &amp; Wassersug  <b>Year of study:</b> 2010-2011  <b>Site:</b> Online international (respondents from 17 countries)  <b>Language:</b> English  <b>Funding:</b> Unfunded</p>	<p><b>Design:</b> Controlled online survey with open-ended questions about sexual activity before and after prostate cancer treatment  <b>Participants:</b> 96 nonheterosexual and 460 heterosexual men  <b>Recruitment:</b> Unvalidated sample recruited from 40 prostate cancer support organizations, including online support groups; no compensation  <b>Criteria:</b> No exclusions</p>	<p><b>Sexual effects:</b> Results not formally analyzed or broken out by sexual orientation. However, the authors in the discussion describe nonheterosexual men as more "adventurous" in exploring novel sexual options than heterosexual men.<sup>30</sup></p>

**TABLE 1.2**

Qualitative Studies with  $N > 5$  Participants ( $N = 8$  Studies)

	Study Logistics	Methods (Design, Recruitment, Participants, Procedures)	Key Results
4	<p><b>PI:</b> Doran  <b>Year of study:</b> Not specified (pre-2015)  <b>Site:</b> U.K.  <b>Language:</b> English  <b>Funding:</b> Not specified</p>	<p><b>Design:</b> 12 semistructured interviews  <b>Participants:</b> 12 gay men  <b>Procedures:</b> Not specified (abstract)  <b>Inclusion/exclusion criteria:</b> Not specified (abstract)</p>	<p><b>General life effects:</b> Using Merleau-Ponty's four life world existentials, themes that emerged include: (1) <i>corporeality</i>: bodily effect of the disease, including violation of identity, assault of the physical body, and power of potency; (2) <i>temporality</i>, including threat to eternal youth; living in a state of flux; disrupted lives; and past, present, and future horizons; (3) <i>relationality</i>, including quest for mutual respect and equality, locating information, to tell or not to tell, changes and challenges, friendship and pursuit of peers; and (4) <i>spatiality</i>, including yearning for community, the power of proximity, and isolation.<sup>92</sup></p>
5	<p><b>PI:</b> Thomas  <b>Year of study:</b> Not specified (pre-2013)  <b>Site:</b> Australia  <b>Language:</b> English  <b>Funding:</b> Not specified</p>	<p><b>Design:</b> Asynchronous online focus group transcript analysis  <b>Participants:</b> 10 GBM  <b>Recruitment:</b> Informally through prostate cancer support groups for GBM  <b>Inclusion/exclusion criteria:</b> Had to be Australian diagnosed with prostate cancer within last 7 years</p>	<p><b>General effects:</b> Some participants reported a positive perspective post-diagnosis and adopted a sense of empowerment. Participants spoke about emotional responses to a diagnosis of prostate cancer, accessing help and support, the effect of incontinence, the influence of sexual changes on identify, a reevaluation of life, changed sexual relationships, the need to find the most suitable healthcare professionals, and identification of current needs to improve quality of care. Authors conclude that the psychological effects of prostate cancer may be quite significant over an extended time frame.<sup>42</sup></p>
6	<p><b>PI:</b> Lee  <b>Year of study:</b> Not specified (pre-2015)  <b>Site:</b> Vancouver, B.C.  <b>Language:</b> Not specified  <b>Funding:</b> Canadian Association of Radiation Oncology Award; Canadian Institutes of Health; Eli Lilly</p>	<p><b>Design:</b> 14 in-depth semistructured in-person interviews and 2 videophone interviews  <b>Participants:</b> 16 MSM  <b>Recruitment:</b> From clinics, gay Pride events, Facebook and Craigslist  <b>Exclusion criterion:</b> Restricted to &lt; 75 years</p>	<p><b>Sexual effects:</b> Treatment resulted in (1) erectile, urinary, ejaculation, and orgasmic dysfunctions; (2) challenges to intimate relationships; and (3) lack of MSM-specific oncological and psychosocial support for survivors. Negative effects on quality of life can be severe for MSM and require targeted attention.<sup>93</sup></p>

(continued)

**TABLE 1.2** (continued)

Qualitative Studies with  $N > 5$  Participants ( $N = 8$  Studies)

	Study Logistics	Methods (Design, Recruitment, Participants, Procedures)	Results
7	<p><b>PIs:</b> Rosser &amp; Capistrant  <b>Name of study:</b> Restore  <b>Year of study:</b> 2015  <b>Site:</b> U.S. and Canada  <b>Language:</b> English  <b>Funding:</b> National Cancer Institute (NCI, R21); American Cancer Society</p>	<p><b>Design:</b> In-depth semistructured telephone interviews  <b>Participants:</b> 30 GBM treated for prostate cancer: 19 with radical prostatectomy, 6 with radiation; 5 systemic  <b>Recruitment:</b> Online support group  <b>Inclusion/exclusion criteria:</b> Must have received surgery, radiation, or systemic treatment for prostate cancer; must be resident in the United States or Canada</p>	<p><b>Social support:</b> GBM receive variable but generally low social support during diagnosis and treatment. Compared to heterosexual survivors who rely on spouse and biological family, GBM rely more on self, partner, and chosen family.<sup>62</sup></p> <p><b>Sexual effects (<math>N = 19</math> GBM with radical prostatectomy):</b> Major challenges to sexual functioning included anatomical changes to the penis, loss of ejaculate, climacturia, erectile dysfunction, and possibly decreased libido. All forms of sexual behavior with other men, not just penetrative sex, appeared affected and affected across all stages of the sexual response cycle. Some GBM reported shifting their role-in-sex after surgery; others engaged in novel substitution behaviors.<sup>29</sup></p> <p><b>Mental health, identity, and relationships (<math>N = 19</math> radical prostatectomy):</b> Five emotional themes emerged: (1) shock at the diagnosis, (2) a reactive depression, (3) sex-specific situational anxiety, (4) grief, and, (5) an enduring loss of sexual confidence. Identity challenges included loss of a sense of maleness and manhood, changes in strength of sexual orientation, role-in-sex identity, and immersion into sexual subcultures. Identified relationship challenges included disclosing the sexual effects of treatment to partners, loss of partners, and renegotiation of sexual exclusivity. Most to all of these effects stem from sexual changes.<sup>68</sup></p>

**TABLE 1.2**

Qualitative Studies with  $N > 5$  Participants ( $N = 8$  Studies)

	Study Logistics	Methods (Design, Recruitment, Participants, Procedures)	Results
8	<p><b>PIs:</b> Ussher &amp; Perz</p> <p><b>Year of study:</b> 2015–2016)</p> <p><b>Site:</b> Global (mainly Australia, U.S., U.K.)</p> <p><b>Language:</b> English</p> <p><b>Funding:</b> Prostate Cancer Foundation of Australia (PCFA)</p>	<p><b>Design:</b> Mixed methods using answers to open-ended and closed questions plus in-person or video interviews</p> <p><b>Participants:</b> 124 GBM and 21 male partner survey respondents, and 46 GBM and 7 partners interviewed</p> <p><b>Recruitment:</b> Cancer support groups, cancer research databases, clinicians, social media, and GB community and health organizations</p> <p><b>Inclusion:</b> Diagnosis of prostate cancer</p>	<p><b>Sexual effects:</b> 72% of survey respondents reported erectile dysfunction, which was associated with emotional distress, negative effect on gay identity, and feelings of sexual disqualification. Other sexual concerns included loss of libido, climacturia, loss of sensitivity or pain during anal sex, non-ejaculatory orgasms, and reduced penis size. Many of these outcomes led to feelings of exclusion from the gay community. Other men reported being reconciled to sexual changes, identified no challenge, and engaged in sexual renegotiation.<sup>43</sup></p> <p><b>GBM-physician communication:</b> Four themes emerged: (1) cancer-centered care negates sexual needs; (2) healthcare professionals assume heterosexuality of their patients; (3) navigating sexual orientation disclosure (avoidant vs. hesitant vs. forthright); and (4) healthcare professionals' responses to disclosure and requests for gay-specific information (rejecting vs. lack of knowledge or interest vs. acknowledgment and interest).<sup>94</sup></p>

incidence compared to the general population during the pre-PSA (and pre-ARV) time period (before 1992) but a significant twofold reduction in risk among those with AIDS during the PSA era (1992–2007).<sup>20</sup>

Why HIV-positive men would be at less risk for prostate cancer than HIV-negative men warrants more investigation. Unfortunately, the HIV studies to date have not reported data on sexual orientation, so it is impossible to tease out what may be HIV effects from effects due to sexual orientation. A Chicago-based study found that HIV-positive men were as likely to receive treatment for prostate cancer, less likely to undergo a radical prostatectomy, and more likely to be overtreated compared to HIV-negative men.<sup>21</sup> The authors concluded that while the rate of AIDS-defining cancers among HIV-positive men continues to fall, as HIV-positive men live longer, the rate of non-AIDS-defining cancers (such as prostate cancer) may rise. Though HIV and immuno-



**TABLE 1.3**

Key Results from Quantitative Studies of Prostate Cancer Outcomes in GBM  
 (N = 12 Papers from 8 Studies)

Study Logistics	Methods	Prostate Cancer Sexual, Urinary, Bowel, Hormonal Outcomes	Other Results
<b>PI:</b> Motofei <b>Year of study:</b> 2008 <b>Site:</b> Bucharest, Romania <b>Language:</b> Romanian <b>Funding:</b> Not specified	<b>Design:</b> Comparative drug treatment trial with 5-week follow-up <b>Participants:</b> 12 homosexual and 17 heterosexual <b>Recruitment:</b> From local hospital <b>Eligibility validation:</b> From hospital records <b>Criteria:</b> Diagnosed, treatment-naïve prostate cancer patients presenting at local hospital	GBM had worse sexual functioning than heterosexual men following treatment with bicalutamide. <sup>106</sup>	—
<b>PIs:</b> Allensworth-Davies & Clark <b>Year of study:</b> 2010 <b>Site:</b> U.S. <b>Language:</b> English <b>Funding:</b> National Cancer Institute (NCI, R03)	<b>Design:</b> Uncontrolled, cross-sectional survey <b>Participants:</b> 111 gay-identified men <b>Recruitment:</b> Through gay print magazines <b>Validation:</b> None <b>Criteria:</b> Minimum 50 years of age; self-identify as gay only; must have been treated for at least one year for localized prostate cancer	Gay men report significantly lower urinary and bowel functioning than 341 heterosexual men.*	Younger gay prostate cancer survivors and men who reported recent severe stigma report lower masculinity self-esteem scores than men 75+ years old. <sup>99</sup>
<b>PI:</b> Lee <b>Year of study:</b> 2011–2012 <b>Site:</b> Ottawa, Canada <b>Language:</b> Not specified <b>Funding:</b> Unfunded	<b>Design:</b> Uncontrolled cross-sectional mailed pen-and-paper survey <b>Participants:</b> 15 MSM <b>Recruitment and validation:</b> From urology and oncology departments at local hospital <b>Criteria:</b> Must have received prostate cancer treatment; excluded if had androgen deprivation within 18 months or had chemotherapy/noncutaneous malignancies	GBM have worse urinary, bowel, ejaculatory function and sexual bother than published norms. <sup>27</sup>	—

**TABLE 1.3**

Key Results from Quantitative Studies of Prostate Cancer Outcomes in GBM  
 (N = 12 Papers from 8 Studies)

Study Logistics	Methods	Prostate Cancer Sexual, Urinary, Bowel, Hormonal Outcomes	Other Results
<b>PI:</b> Hart <b>Year of study:</b> Not specified (pre-2011) <b>Site:</b> Online U.S. and Canada <b>Language:</b> Not specified <b>Funding:</b> University internal funding	<b>Design:</b> Uncontrolled cross-sectional online survey <b>Participants:</b> 92 self-identified gay or bisexual men <b>Recruitment:</b> Through listservs, community centers, support groups, and advertisements in local media <b>Eligibility validation:</b> By phone screening <b>Criteria:</b> Diagnosis of prostate cancer within last 4 years; no exclusions	GBM have worse urinary, bowel, and hormonal functioning and bother than published norms, worse mental health functioning, greater fear of cancer recurrence, and better sexual functioning than published norms. <sup>25, 59</sup>	Outness (as GBM) mediates anxious attachment and more illness intrusiveness. Facilitating GBM to be out may benefit illness adjustment. <sup>100</sup> Worse bowel, hormone, and sex function predicts fear of prostate cancer recurrence, mediated by self-efficacy and satisfaction with care. <sup>103</sup>
<b>PIs:</b> Dowsett & Wassersug <b>Year of study:</b> 2010–2011 <b>Site:</b> Online international (respondents from 17 countries) <b>Language:</b> English <b>Funding:</b> Unfunded	<b>Design:</b> Controlled online survey <b>Participants:</b> 96 nonheterosexual and 460 heterosexual men <b>Recruitment:</b> Sample recruited from 40 prostate cancer support organizations, including online support groups; no compensation <b>Eligibility validation:</b> Sample not validated for eligibility <b>Criteria:</b> No exclusions	GBM have lower Gleason scores and greater ejaculatory bother than heterosexual men. No differences on incidence of urinary incontinence, bone pain, or antidepressant use. <sup>26</sup>	GBM versus heterosexual survivors differ by country of residence and relationship status. Many GBM cope with ED by changing their role-in-sex. <sup>30</sup>
<b>PI:</b> Mitteldorf <b>Year of study:</b> 2015 <b>Site:</b> U.S. <b>Language:</b> English <b>Funding:</b> Unfunded	<b>Design:</b> Controlled online survey <b>Participants:</b> 148 GBM and 632 heterosexual men <b>Recruitment:</b> Sample recruited from large online prostate cancer support group <b>Eligibility validation:</b> Sample not validated for eligibility <b>Criteria:</b> Inclusion criteria not specified (abstract only)	—	In unadjusted analyses, GBM report more early-stage treatments but fewer advanced-stage treatments than heterosexual men. <sup>101</sup>

*(continued)*

**TABLE 1.3** (continued)

Key Results from Quantitative Studies of Prostate Cancer Outcomes in GBM  
(*N* = 12 Papers from 8 Studies)

Study Logistics	Methods	Prostate Cancer Sexual, Urinary, Bowel, Hormonal Outcomes	Other Results
<p><b>Study:</b> Restore Aim 1  <b>PI:</b> Rosser  <b>Year of study:</b> 2015  <b>Site:</b> Online U.S. and Canada  <b>Language:</b> English  <b>Funding:</b> National Cancer Institute (NCI, R21)</p>	<p><b>Design:</b> Natural experiment: GBM offered screening and interview online, by Skype, or by phone  <b>Participants:</b> <i>N</i> = 74 GBM screened and 30 interviewed  <b>Eligibility validation:</b> Validated through in-depth interview**  <b>Recruitment:</b> From e-mails sent to online support groups  <b>Criteria:</b> Must have been treated for prostate cancer, residing in U.S. or Canada; compensated</p>	<p style="text-align: center;">—</p>	<p><b>Research methods:</b> For qualitative interviews, GBM with prostate cancer preferred being screened online but interviewed by phone.<sup>102</sup></p>
<p><b>Study:</b> Restore Aim 3  <b>PI:</b> Rosser  <b>Year of study:</b> 2015–2016  <b>Site:</b> Online U.S. and Canada  <b>Language:</b> English  <b>Funding:</b> National Cancer Institute (NCI, R21)</p>	<p><b>Design:</b> Uncontrolled online survey  <b>Participants:</b> 193 self-identified GBM  <b>Recruitment:</b> Through large online prostate cancer support group  <b>Eligibility validation:</b> Sample was cross-validated through de-duplication and cross-validation protocol (55% excluded)  <b>Criteria:</b> Must have been treated for prostate cancer; residing in U.S. or Canada; compensated</p>	<p>GBM have worse urinary and hormonal function and worse hormonal bother, but better sexual function and less bother than published norms.<sup>130</sup></p>	<p>66.6% describe their sexual function post-treatment as fair to poor. ED was common, severe, and pervasive across sexual behavior; it was also a major reason for not using condoms. 33.3% reported receptive anal sex difficulties. ED, non-condom use, anodyspareunia, and all sexual functions were problematic.<sup>130</sup> Needs assessment shows high interest in an online sexual recovery program tailored to GBM with prostate cancer.<sup>131</sup></p>

**TABLE 1.3**

Key Results from Quantitative Studies of Prostate Cancer Outcomes in GBM  
 (N = 12 Papers from 8 Studies)

Study Logistics	Methods	Prostate Cancer Sexual, Urinary, Bowel, Hormonal Outcomes	Other Results
<b>PIs:</b> Ussher & Perz <b>Year of study:</b> 2015–2016 <b>Site:</b> Australia, U.S., U.K., and global <b>Language:</b> English <b>Funding:</b> Prostate Cancer Foundation of Australia (PCFA)	<b>Design:</b> Controlled online survey <b>Participants:</b> 124 MSM and 225 heterosexual men <b>Recruitment:</b> MSM recruited through urology and general practice clinics, prostate cancer support groups, and social media. Heterosexual comparison group recruited through cancer research volunteer databases <b>Eligibility validation:</b> Sample not validated for eligibility <b>Criteria:</b> Must have been diagnosed with prostate cancer	GBM report lower quality of life; higher psychological distress; lower masculine self-esteem; lower sexual confidence and sexual intimacy; lower satisfaction with treatment; and ejaculatory concern. <sup>105</sup>	GBM prostate cancer survivors were significantly younger than heterosexual sample. ED was reported in 72% of GBM. Loss of libido, climacturia, anodyspareunia, orgasm, and penile size are all problematic. <sup>105</sup>
*This is an unpublished thesis result, noted in two other published papers. <sup>25, 107</sup> ** Eligibility validation denotes a best practice in online survey research to confirm that the surveys come from eligible, valid, unique participants. Methods of validation include some combination of external validity checks (e.g., hospital records, driver's license), electronic validation (e.g., Captcha), telephone validation, and cross-validation and de-duplication protocols. <sup>132, 133</sup>			

deficiency may alter the risk of prostate cancer<sup>11, 12, 22, 23</sup> and cancer virulence,<sup>11</sup> ARV treatment appears to be protective.<sup>24</sup>

**5. Do GBM have different treatment outcomes from other men?** Yes. GBM appear to have worse urinary and possibly bowel outcomes, but better sexual outcomes, than published norms.<sup>25–27</sup> Why GBM report poorer urinary and bowel function than heterosexual men is not clear. Some studies conclude that the better sexual outcomes GBM report compared to heterosexual peers may be due to GBM being more open, innovative, or committed to restoring their sexual function.<sup>28, 29</sup> Substantial differences in role-in-sex, pre- and post-treatment, have also been reported,<sup>25</sup> which may also influence outcomes. GBM report more bother as a result of the inability to ejaculate than heterosexual men.<sup>26, 105</sup>

**6. Do GBM receive different treatment from heterosexual men?** Possibly. In one study, Gleason scores were significantly lower for GBM than for heterosexual men, which suggests that GBM may be diagnosed ear-

lier than heterosexual men.<sup>26, 30</sup> While the authors speculate that GBM may be more likely to undergo regular health checkups, this explanation is at odds with the data reporting lower, not higher, PSA testing among MSM.<sup>10</sup> Because vigorous stimulation of the prostate may significantly affect the serum PSA,<sup>31</sup> GBM and TGW should be warned to refrain from receptive anal stimulation for at least 48 hours before a PSA test.<sup>11</sup> Studies of how clinicians test PSA in GBM are needed to examine whether invalid PSA testing is contributing to this disparity. A second hypothesis is that physical trauma to the prostate (e.g., from repeated receptive anal sex) could increase serum PSA levels.<sup>15</sup>

LGBT health disparities in accessing medical care exist.<sup>2</sup> GBM may experience prostate cancer treatment as heteronormative.<sup>32-34</sup> GBM with prostate cancer report that healthcare providers fail to ask about sexual orientation during initial consultations, may assume they are not sexually active, or assume they are heterosexual.<sup>35</sup> Goldstone notes that in his experience as a surgeon, gay men may be embarrassed to ask about sexual function.<sup>36, 37</sup> There remains a lack of prostate cancer educational resources tailored to gay men (see also chapter 6 in this book).<sup>38</sup>

### **7. What are the known psychological effects of treatment on GBM?**

Like other men, GBM report reduced sense of masculinity,<sup>39-41</sup> identity,<sup>42, 43</sup> or self-esteem (or a combination of these).<sup>44-47</sup> The sexual effects of prostate cancer carry a stigma leading some GBM to conclude they are less sexually desirable than other GBM.<sup>42</sup> Prostate cancer in GBM intersects with issues of minority status,<sup>35, 48</sup> discrimination,<sup>35</sup> stigmatization,<sup>35, 44</sup> less familial support,<sup>6, 7, 49-51</sup> and less social support.<sup>7, 49-51</sup> Though some GBM may develop "an inner strength to meet the challenges of prostate cancer,"<sup>42</sup> others report profound shame at their own ignorance about prostate cancer,<sup>52</sup> grief at the diagnosis,<sup>42</sup> poor body image after treatment,<sup>53</sup> and premature aging.<sup>54</sup> For HIV-positive GBM, prostate cancer may be one more medical complication to address in an already medicalized life.<sup>48</sup>

### **8. What are the specific challenges of prostate cancer treatment for GBM?**

While prostate cancer affects GBM in many of the same ways as heterosexual men, GBM prostate cancer survivors face unique challenges, including the loss of the prostate as a site for sexual pleasure in receptive sex,<sup>11, 49</sup> loss of ejaculate (which authors emphasize is more central in gay sex),<sup>35, 52, 54</sup> persistent rectal irritation or pain sufficient to

prevent receptive anal sex,<sup>36, 55</sup> and erections too weak for insertive anal sex.<sup>52</sup> Anal penetration is estimated to require 33 percent more rigidity than vaginal penetration.<sup>56</sup> In one study, most (59%) GBM reported changes in anal intercourse after treatment; almost half (46%) ceased it.<sup>30</sup> Weak erections may prevent GBM treated for prostate cancer from using condoms, increasing the risk of HIV transmission.<sup>57</sup> And changes in role-in-sex can occur. Before treatment, 58 GBM were insertive partners; of these, 14 (24%) changed to being exclusively receptive partners after treatment. None of the GBM who were exclusively receptive before treatment changed roles afterward.<sup>30</sup>

**9. What do we know about interventions to assist mental health and quality of life for GBM?** Prostate cancer and its treatment have significant effects on mental health<sup>35, 58</sup> as well as quality of life.<sup>59</sup> Race or ethnicity and sexual minority status are significant negative predictors of quality of life after treatment for prostate cancer.<sup>60</sup> Case studies of GBM with prostate cancer confirm significant post-treatment mental health challenges.<sup>61</sup> Blank concludes that though the poorer sexual outcomes for GBM need research, the negative quality-of-life effect of treatment adds urgency.<sup>55</sup>

**10. What social supports do GBM receive?** Compared to heterosexuals, GBM experience less familial<sup>6, 7, 49–51</sup> and social support.<sup>7, 49–51</sup> Social support is structured differently for GBM with prostate cancer.<sup>38, 62</sup> Because GBM are less likely than heterosexuals to have a partner, children, or religion-based support systems, they are more likely to go through treatment either alone or by relying on parents, chosen family, or hired help.<sup>62</sup> For GBM, case reports affirm the importance of talking to other GBM about their cancer.<sup>35, 58, 63, 64</sup> However, general support groups for men with prostate cancer may adversely affect GBM if GBM feel alienated from discussing their sexual concerns.<sup>63</sup> While support groups specifically for GBM with prostate cancer may be ideal, in all but the largest cities they may not be viable.<sup>64</sup> Instead, one-on-one peer support from a GBM prostate cancer survivor<sup>63</sup> and online support groups for GBM<sup>58, 64</sup> appear to be the two forms of prostate cancer support most commonly accessed. The effects of such support have not been evaluated.

**11. How does prostate cancer change gay relationships?** Some relationship researchers term prostate cancer a “couple’s disease” because the

illness and treatments affect the well-being of both the patients and their partners.<sup>65</sup> Partner involvement in prostate cancer treatment in heterosexual couples improves outcomes;<sup>66</sup> however, GBM may be less likely to involve their male partners in treatment.<sup>49</sup> We found three case reports documenting effects of prostate cancer on gay male couples.<sup>61, 63, 67</sup> Gay couples may engage in novel accommodation practices, including change in roles-in-sex and open relationships, that have not been noted in heterosexual couples.<sup>67, 68</sup> More research is needed to include the effects of prostate cancer treatment on partners, relationships, and gay couples' agreements.<sup>63</sup> Given gender differences, the literature on female partners of men with prostate cancer should be extrapolated to male partners only with extreme caution. Male partners may have unique concerns, such as fear of infectivity, that female partners may not experience. Caring for a partner with prostate cancer may be experienced differently by male spouses.<sup>63</sup> In addition, prostate cancer's effect on single GBM<sup>49</sup> and casual sex partners needs more research.<sup>35, 55</sup>

## **DISCUSSION**

Multiple studies all describe prostate cancer in GBM as a severely under-researched area.<sup>2, 8</sup> As evidenced by 88 unique citations, that situation is changing. The key finding of this review is that a small but robust literature is emerging on the experience of GBM prostate cancer survivors. The same cannot be said of TGW, where the literature is limited to a single case report every two to three years. Multiple challenges have stymied research in this area. Health research on GBM for the last 30 years has focused on HIV/AIDS, which has left chronic diseases in GBM almost unstudied.<sup>2</sup> Now, because ARV treatments have greatly reduced AIDS mortality, large cohorts of GBM are entering age groups in which prostate cancer is commonly diagnosed. Recruitment of GBM in meaningful numbers for study is also a barrier, exacerbated by a lack of sexual history taking as standard practice, as well as clinical systems not collecting systematic data on sexual orientation or gender of sexual partners. This situation leaves GBM with prostate cancer as an invisible, geographically dispersed, hard-to-recruit population.

Language is a separate challenge. As tables 1.2 and 1.3 show, there is no consistent term used for GBM, and whether TGW are included or excluded varies across studies. Similarly, prostate cancer professionals

may use the term *survivor* for patients five or more years out, whereas GBM created, and are more familiar with, the nomenclature *persons living with [HIV]*.<sup>69</sup> GBM may not agree with or endorse *survivor* as an identity label. Heterocentric definitions of sexual functioning and scales limited to penetrative sex are problematic. Until recently, erectile functioning in prostate cancer treatment was operationalized as “sufficient for vaginal penetration.”<sup>55, 70, 71</sup> Population-appropriate measures and definitions will need to be developed before the effects of prostate cancer treatment in GBM can be enumerated.

Six directions for future research are identified. First, methodological research is needed to identify ways to locate, recruit, and retain GBM with prostate cancer in studies and to develop population-appropriate definitions and measures. Second, as the results detail, more formative research in specific areas is needed. Third, empirical studies to quantify the prevalence and incidence of problems, and the effects of different treatments, will be critical to informing clinical care. Fourth, comparative studies of treatment preferences for GBM and heterosexual men should confirm whether GBM are more likely than, as likely as, or less likely than heterosexuals to choose surgical intervention. Fifth, intervention studies to address the rehabilitation needs of GBM with prostate cancer are critical to develop evidence-based interventions tailored to this population. Finally, the training needs of urologists, surgeons, oncologists, and other specialists providing services to GBM with prostate cancer remain to be identified, and curricula developed, to ensure culturally competent providers capable of addressing the sexual health needs and care of this population.

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HPV is associated with anal cancer in men who have sex with men. Get tested and have your partner tested. Don't have unprotected sex unless you're certain you and your partner aren't infected with HIV or other sexually transmitted infections. Gay men are more likely to experience body image problems and eating disorders, such as anorexia and bulimia nervosa, than are their straight counterparts. One potential explanation is that, as a result of growing up with images of slender and effeminate gay men or men with muscular bodies, some gay and bisexual men worry excessively about their weight. If you're struggling with body image concerns or an eating disorder, get help. The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Healthcare. Philadelphia, Pa. Recent papers in Gay Men's Sexual and Mental Health. Papers. People. Much of the research on men and prostate cancer has neglected gay and bisexual men. Assumptions are made that gay men are men too, so they must have the same experiences as heterosexual men. Recent research, however, has shown marked more. The future of drugs: recreational drug use and sexual health among gay and other men who have sex with men. There are complex historical connections between sexual minoritisation and desires to chemically alter bodily experience. For gay men, drug and alcohol use can be a creative or experimental response to social marginalisation and not more. The majority of gay men and lesbians reported having completely or very accepting families; for transgender and bisexual respondents, these percentages were lower (42 and 24 percent, respectively). Almost one-third (31 percent) of bisexuals said family members were not very or not at all accepting, a far higher percentage than the next least-accepted subpopulation of transgender people (12 percent). In his secondary analysis of 372 men aged 50-85 in the Urban Men's Health Study—a probabilistic sample of men who have sex with men obtained in San Francisco, Los Angeles, Chicago, and New York using a modified random-digit dialing approach—Rawls (2004) found that almost 5 percent of the men in this sample had never told someone they were.