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The Effects of Radical Prostatectomy on Gay and Bisexual Men's Mental Health, Sexual Identity and Relationships: Qualitative Results from the *Restore* Study

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Abstract

The effect of prostate cancer treatment in gay and bisexual men is an under-researched area. In 2015, we conducted in-depth telephone interviews with 19 gay and bisexual men who had undergone radical prostatectomies. Across the respondents' five emotional themes emerged: (1) shock at the diagnosis, (2) a reactive, self-reported "depression", (3) sex-specific situational anxiety, (4) a sense of 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 sub-cultures. Relationship challenges identified included disclosing the sexual effects of treatment to partners, loss of partners, and re-negotiation of sexual exclusivity. Most to all of these effects stem from sexual changes. To mitigate these negative effects of radical prostatectomy, and to address health disparities in outcomes observed in gay and bisexual men, all these challenges need to be considered in any tailored rehabilitation program for gay and bisexual men.

Background

Almost no research has examined the effects of radical prostatectomy on the mental health, sexual identity and relationships of gay and bisexual men (GBM). The literature is so sparse that Perlman and Descher note, “If prostate cancer, in general, is off most people’s radar screen, then gay men with prostate cancer are a truly invisible species”(Perlman & Drescher, 2005, p. 2).

From research on heterosexual men, it is clear prostate cancer and its treatment can have profound effects on survivors’ mental health(J. Harden et al., 2002; Litwin, Lubeck, Spitalny, Henning, & Carroll, 2002), identity, and relationships(J. Harden et al., 2002). In terms of mental health, studies of (heterosexual) prostate cancer survivors identify psychological distress(Roth et al., 1998), depression(Nelson et al., 2009), anxiety, fear and uncertainty(Denberg, Melhado, & Steiner, 2006), as the dominant emotional/mental health challenges. In men treated for prostate cancer, their levels of mental health - as measured by the SF-36-item subscale on emotional well-being - worsen immediately after diagnosis(Litwin et al., 2002), possibly returning to pre-diagnosis levels at longer term follow-up(Korfage, de Koning, Roobol, Schröder, & Essink-Bot, 2006). Not all survivors’ mental health appears equally affected, however. Men who had radical prostatectomies scored significantly better on this measure over time than men who underwent pelvic radiation or watchful waiting(Litwin et al., 2002). (This confirms the need to analyze the mental health effects of prostate cancer treatment by type of treatment). Prostate survivors of lower socioeconomic status (SES) report lower scores on the mental health subscale than prostate survivors with higher SES (despite no differences in physical outcomes)(Aarts et al., 2010). Compared to younger men with prostate cancer, older men with prostate cancer reported less distress and less anxiety, but greater depressive symptoms(Nelson et al., 2009).

For identity, two effects of prostate cancer treatment in heterosexual men include a decreased sense of manhood/masculinity(Blank, Bellizzi, Murphy, & Ryan, 2003; David T Eton & Stephen J Lepore, 2002; Gotay, Holup, & Muraoka, 2002; Gray, Fitch, Fergus, & Mykhalovskiy, 2002; Roth, Weinberger, & Nelson, 2008) and a loss of sexual self-esteem(Blank, 2008; Chapple & Zieband, 2002; D.T. Eton & S.J. Lepore, 2002; Fergus, Gray, & Fitch, 2002), both assumed to be secondary to altered sexual function.

For relationships, the literature is mixed. While wives of patients with prostate cancer report more distress than their husbands(Cliff & MacDonagh, 2000; D.T. Eton & S.J. Lepore, 2002; Maliski, Heilemann, & McCorkle, 2002), some studies characterize heterosexual men as struggling to communicate to their wives (especially emotionally and about sexual dysfunction) (Boehmer & Clark, 2001a, 2001b), resulting in increased marital distress (Badr & Carmack Taylor, 2009). Other studies report an increase in shared meaning (Maliski et al., 2002), and improvement in heterosexual relationships following treatment (Janet Harden et al., 2002; Lavery & Clarke, 1999), attributed to reduced discrepancies in levels of sexual interest. (Canaday, 2003) Still others report both positive and negative effects on primary relationships (Janet Harden et al., 2002), dependent on such factors as dyadic cohesion, the degree of the man's sexual dysfunction, and pre-diagnosis marital satisfaction.

Far less is known about GBM with prostate cancer. For mental health, emerging evidence suggests that outcomes may be worse for GBM than published norms (for predominantly heterosexual samples). In a North American study of 92 gay-identified men treated for prostate cancer, respondents scored significantly worse on the mental health composite scale of the Medical Outcomes Study Short Form (SF-36) than published norms (Hart, Coon, Kowalkowski, & Latini, 2011). As elevated depression in GBM (without prostate cancer) is well documented (Cochran, Sullivan, & Mays, 2003; Mills et al., 2004), we caution against inferring anything about prostate cancer treatment causally and differentially impacting GBM's mental health and well-being.

GBM may experience greater mental health challenges and less emotional support, post-treatment. As a group, lesbian, gay and bisexual adults "appear to experience more mood and anxiety disorders, more depression, and an elevated risk for suicidal ideation and attempts compared with heterosexual adults" (Institute of Medicine, 2011). In addition, prostate cancer in GBM intersects with issues of minority status (Mitteldorf, 2005), discrimination (Mitteldorf, 2005) and stigmatization (Fergus et al., 2002; Mitteldorf, 2005), including less familial (Kurdek, 2001, 2004a, 2004b, 2005; Smith, Filiault, Drummond, & Knappman, 2007) and social support (Kurdek, 2001, 2004b, 2005; Smith et al., 2007), and less partner involvement in treatment (Smith et al., 2007).

In the authors' review of the literature (Rosser et al., 2016), we could find only one abstract of a doctoral dissertation and three case reports examining the effects of treatment on GBM's mental health, identity, and relationships. The doctoral dissertation compared 341 heterosexual men with 111 gay men, finding GBM to report lower masculine self-esteem and less partner affection than heterosexual men with prostate cancer (Allensworth-Davies, 2012). The author posits that greater sensitivity to stigma as a sexual minority could result in poorer overall quality of life compared to heterosexual men. However, this study has not been peer reviewed or published.

In the first case report, in reaction to diminished sexual performance, libido, and loss of spontaneity, the patient reports fear, anger, and frustration, shifts in role in sex, and worry about keeping his (younger) partner (Higgins, 2005). In the second, a gay man details his own and his partner's reaction to radical prostatectomy; including for both men, depression, anxiety, and anger (Parkin & Girven, 2005). In the third, acknowledging, accommodating, and accepting change in sexual experience emerged as meta themes across three same sex couples, interviewed (Hartman et al., 2014). The authors note that gay couples may engage in novel accommodation practices such as change in role in sex and open relationships, that have not been noted in heterosexual couples (Hartman et al., 2014).

While these case studies are interesting, they are anecdotal. We could find no systematic, in-depth, published studies of the effects of radical prostatectomy surgery on any of these aspects of GBM's lives. To address this gap in the literature, we conducted in-depth semi-structured interviews with GBM treated for prostate cancer. Because the effects of treatment vary by treatment type, we limited this analysis to men who had undergone radical prostatectomy.

Methods

The methods in this study are reported in detail, elsewhere (see companion paper in this issue).

Content analysis and grounded theory approaches guided this specific data analysis. Two investigators independently undertook a coding process that involved line-by-line coding – inductive and deductive -- of the transcribed interview. Individual codes were then organized into larger categories and any differences between coders, resolved by the larger team. This process of bringing findings to the larger investigator team served as a form of expert review and offers analytic validity to this study.

Findings

In addition to other findings of the companion article in this edition summarized in that paper's figure, we present here findings related to emotional and mental health, identity, and disclosure and relationship challenges, respectively (Figure 1).

1. Emotional and Mental Health Challenges

Five themes emerged from the participants' narratives about the emotional impact of prostate cancer and its treatment. All participants reported an initial shock reaction to the diagnosis; followed, for some, by a reactive depression during the first year post treatment, and/or an ongoing situational anxiety focused on sex. Multiple participants expressed grief around the loss of spontaneity in sex and others manifested an enduring loss of sexual confidence.

(a) Reaction to the diagnosis

All participants reported feeling shocked, scared, and/or terrified by their diagnosis. This was true whether the man reported an extensive family history or no history of prostate cancer. Men with a familial history of prostate cancer put the diagnosis into their familial context (describing themselves as shocked, but not surprised), while those without a familial history reported both shock and surprise. Younger men and those who reported otherwise being in good health expressed additional shock because of their age and/or health status.

“Scary and felt inevitable. I have a long family history...routine screen, which started earlier because of my family history. My father died of prostate cancer in 2001; my grandfather died of it in 1982. My brother was diagnosed in 2003 and treated, he's still alive. I have a cousin who is stage 4. I was the youngest of everybody to get it, so I think I was surprised that it happened so soon. [I was] forty-three. [MSU03]

“Initially shocking, because I was only 52, and I thought I was in extremely good health, and then terrifying because I just assumed I was going to die soon.... It was just absolute and utter disbelief mostly because I thought I was so fit and I thought I was so healthy.” [MSU04]

(b) “Depression”

In addition to shock, many participants disclosed a depressive period, usually in the first year, immediately post-surgery. Although this self-reported depressive period may differ from clinical definitions of depression, it is notable that participants themselves used the term “depression,” such that we note it in quotations. They described their “depression” as being focused on loss and mourning of their sexual behavior or prior sexual self.

“I wasn't suicidal - I was just very depressed.”[MSU09]

“I think there's always a sense of change and there's always a sense of loss when you go through something like that, particularly when they're removing an organ, and particularly when it's so involved in your sex life. That's not a physical thing, obviously, but it's an emotional response.” [MSU13]

“Afterward, I felt like I would never find another partner again and there was a depression. And I thought well, this is it. I'm just going to be celibate and that kind of thing. But then a friend of mine said try going on the web. And I found other people in my situation and it worked.” [MSU11]

(c) Situational anxiety

Several men expressed an on-going situational anxiety specific to sex and focused to uncertainty about their ability to sexually perform (e.g. with a new partner), or risk of urinary incontinence and/or climacturia.

“Because how traumatic it is, you're with this man that's so physically attractive and so barely touch him and he gets rock hard in a minute, in a second, and you wilt when you're trying to have intercourse. It's just so debilitating emotionally for me. The injections got me beyond that.” [MSU08]

“It's stressful to meet some guy and really want to be with him and want to please him, and to recognize that I may not be able to. What that's done in a funny kind of way is I feel like I'm trapped in hookup hell.” [MSU01]

“Well, we kiss and hug, but we don't get naked together. He's [husband] afraid that I'll dribble on him, so he won't let me get naked with him. He's only done that like twice since I've had surgery. He just is probably turned off by the fact that I could dribble on him. It's kind of put a damper on our intimacy altogether. There's very little intimacy in our relationship.” [MSU17 – underwent surgery 7+ years ago]

(d) Emotional reactions to the sexual effects of treatment: a sense of grief

Many participants described the top two emotional challenges as a sense of grief secondary to the loss of spontaneity, and depression secondary to the loss of sexual self-esteem. Depending on their degree of successful recovery and the type of sexual aid(s) employed, participants report significant emotional loss related to spontaneity describing sex more in terms of a series of difficult challenges to be navigated or an overly planned activity robbed of surprise.

“All sexual spontaneity is gone - anything spontaneous, totally out. Everything has to be planned ahead of time. How much are you drinking? How much salt did you take? Did you take a Cialis? If you're on a date, you may want to have 100 milligram Viagra in your pocket. If you have any chance of going home with somebody, if you want to leave and do that, you can't drink a lot beforehand because you don't want to pee in the guy's bed. All the stuff I never used to think of, ever. It was just wham, bam, thank you, man. You were just much more free. Now, all the spontaneity is gone, which is a shame.” [MSU12] “I think in some ways the physical aspect is easier. It's the emotional and personal toll.” MMSU04]

(e) Loss of sexual confidence

Respondents reported significant loss of sexual confidence variously described as humbling to devastating. Some respondents described themselves as severely damaged or broken as men because of their lack of confidence in their own sexual functioning.

“I would say that the biggest way it's [radical prostatectomy] impacted me is that it has contributed to my lack of confidence in myself as a sexual being. That's the biggest thing. I have a confidence problem anyway ... Having a very unreliable dick, it hurts. It hurts one's self-esteem and one's sense of confidence, and it certainly has mine. I don't feel as viable as a sexual partner whether it's flirting and meeting people or actually having sex.” [MSU19]

“I'm still kind of getting out of this, but for a long time I felt like I was severely damaged; [and] therefore, completely undesirable. I withdrew.” [MSU09]

Participants referred to the emotional adjustment as critically important to address as part of treatment. While one respondent reported being hospitalized for mental health concerns stemming from the surgery, and others respondents reported being referred to sexual rehabilitation therapy, post-surgery, most described sexual rehabilitation as narrowly focused on heterosexual erectile function, and which did not address their emotional reactions.

“In hindsight, that was one thing that I was really disappointed with in [the hospital]. Nobody said anything about the really personal impact on you and the psychological impact on you.” [MSU04]

“My experience with them [prostate cancer specialists] was that they just lump everybody into the same boat. I mean their responses to me had nothing whatsoever do with my sexual orientation. My urologist had a one size fits all approach to it. Well, I'm a reader and a person who gathers information a lot. Much to his credit, he started trying to do an open forum with men who were [just diagnosed] ... Of course, I went to take part and what I found was that there was a lot of information that was being given that was directed toward men who were married, men who were trying to have children, men who were in heterosexual relationships. There was virtually no information geared toward men who were single - heterosexual or homosexual - or men who were in same sex relationship. There was absolutely none geared toward men in same sex relationships.” [MSU01]

Taken together, GBM report multiple emotional and mental health sequelae after undergoing radical prostatectomy.

2. Sexual identity

Each interviewee was asked, How has having prostate cancer changed your sense of being gay or bisexual or your experience as a man who has sex with men? with two follow-up probes, one asking about *changes to their sexual identity*, post-surgery; and the other *about changes to other aspects of their identity*. GBM reported significant identity changes in four areas.

(a) Changes in maleness and being a man

Several men reported that their changes in sexual sensation and erectile challenges had forced their identity to become less focused on the penis and to become more relationally oriented.

“When you have this ... it can be so devastating and your identity has got to be bigger than your penis. ...If you're bisexual, if you're gay, [the] penis is more and more and more important. I just think it's almost a matter of forcing people to re-identify themselves which is a really hard thing to do.” [MSU09]

“I'm more interpersonal with people rather than the typical male thing of being visually stimulated and wanting to act, the testosterone rush. Less testosterone rush, more interpersonal exchange. ... I never quite know how much prostate cancer changed it, or how much the prostate cancer just triggered my own evolution in that direction.” [MSU18]

While these men described their cancer treatment leading to greater intimacy, others described decreased intimacy resulting from the lack of sex.

“What makes it so hard for me ... the time after sex was the time that I was at my most vulnerable. It was the time that I could really open up to somebody. There was no more games after sex. There was no more ‘I'll say whatever I need to say to get laid’. After sex, it was just honesty. That doesn't exist anymore. I never get down to that honesty anymore, and I don't know how to get that back. I don't think you can.” [MSU05]

(b) Changes in sense of being GBM

Although no one stated they had changed from being gay/bi to heterosexual, two changes in aspects of sexual orientation were noted. Two men who had long-term female spouses – one who identified as gay and one as bisexual – following the surgery ceased vaginal sex with their spouse. And some men alluded to the surgery leaving them with a diminished sense of being gay.

“My wife and I no longer have sex, because I'm not sure that I can get enough of an erection for penetration. We do other things but we, I mean, vaginal sex we don't do. I haven't been with a guy since.” [MSU09]

“I feel less than the average gay person.” [MSU17]

Together, these experiences, which reflect a decrease in sexual functioning, may translate also into a diminished sense of gay/bisexual identity (as a primary identity).

(c) Changes in role-in-sex identity

Within the gay community, some GBM may identify themselves according to their role-in-sex labels: “tops” (meaning they identify as preferring insertive sex), “bottoms” (identify as preferring receptive sex) or “versatiles” (identifying as liking both roles). While these role-in-sex labels refer mainly to anal sex preferences, they can also denote preferences in oral sex, and more broadly still, sex role (e.g., “top” can denote responsibility for initiating sex).

Several men in the study, who identified as “tops” pre-surgery, reported both changes in role behavior and identity, principally to address erectile dysfunction.

“I was definitely a 100% top before surgery ... But now, ... well, now I may have to start bottoming more. I'm getting better on the ED part, but still not really good enough, hard enough - no pun intended - for penetration.” [MSU12]

“Now, I'm more a bottom. Now to be a bottom is exciting for me; just the thought of it when I'm with my partner, the thought of it is exciting, so it's part of the whole making love kind of thing. I don't particularly miss [being a top]. ... I feel maybe a little bit regretful that I can't make any hard erection but with age [and] time, [it] goes anyhow.” [MSU02]

Some men, who identify as tops and remain in the top role, report loss of confidence in their abilities as a partner. In addition, some reported experimenting with the bottom role, but concluding they think and function as tops.

“I was always more of the top throughout my life, hardly ever a bottom. I might have tried it once or twice, and I didn't like it. It hurt. After the surgery, it was more difficult to penetrate and still is. I almost don't know if it's psychological or if it's just harder for me because, now, if I were to try topping someone, I feel like I buckle up and I would lose any erection that I have. My mindset is still that of a top. I have tried the bottom role. I can enjoy it with the right sex partner. That's what I thought was kind of strange at the beginning because I figured it was prostate stimulation that really is what the bottom partner enjoyed. I can still enjoy the feeling of being filled sexually. It's more than just physical, for me anyway. I think it's also emotional.” [MSU10]

At least two participants, one identifying as a “top” and one as “versatile”, stated that they could not change their role-in-sex. They also expressed resentment at the assumption that they could or that all gay/bisexual men can easily shift their role-in-sex identity.

“I've gotten to this point where I hate it when people say, ‘Well, you know, as a gay man, you have an option. You can always bottom.’ It isn't that simple. You can't just change your sexual focus like that. ... I don't think I could suddenly become a bottom any more than I could suddenly decide to go out and fly a 747.” [MSU01]

“This situation may put me into a place where I’m more, or maybe even exclusively, a bottom, which I don’t exactly like, but it may be the way things are.” [MSU07]

For bottoms, erectile dysfunction can also lead them to review their role-in-sex.

“I always say I wasn’t the best bottom in the world. ... it wasn’t necessarily something I craved. It’s too bad because that’s one thing you don’t need an erection for it.” [MSU04]

(d) Change in sexual interests and partners

Some men reported solving the challenges of persistent erectile dysfunction by modifying their sexual interests, the “scenes” they are involved in, or lifestyles. Rather than adjusting their role in sex, two respondents reported accommodating their ED and incontinence issues by getting into role-play or bondage; allowing them to be dominant, but not physically sexual.

“I had the mindset of a top. I have one sex partner who likes to be submissive, so, when I have sex with that sex partner, I can be very dominant. We can play bondage games....and it just can work even without the anal penetration.” [MSU10]

One respondent reporting substituting sex with nipple play given the new found sensitivity he experienced, post-surgery.

“The first couple of times (after surgery) you find other things more exciting. Maybe nipple play is, I mean, for me nipple play takes a bigger role in sexual stimulation than I ever thought it would. I guess I substitute with nipple play what might have happened previously.” [MSU02]

Another respondent handled the challenges of sex, post-surgery, by seeking out other men who had received prostate cancer treatment. He described his experience this way:

“I have hooked up with a few men who have had prostate cancer and had the surgery. For some reason, they don’t seem to be as fulfilling as when I have sexual encounters with men who have not had that issue. ... One had to bring a towel with him because he didn’t want to wet my bed because he had those issues. He was hot, but ... that was a bit problematic. Another one just couldn’t get an erection at all, which is okay. I can have a good time with someone even if he doesn’t have a hard-on.” [MSU10]

In summary, the experience of undergoing a radical prostatectomy appears to have had significant effects on multiple aspects of gay and bisexual men’s identity and self-perception.

3. Disclosure and Relationship Challenges

The third major effect gay and bisexual men reported was on how radical prostatectomy changed their relationships with other men.

(a) Disclosing to Partners

For men who were dating and men having sex with new or casual partners, disclosure of their prostate cancer and its sexual effects was identified as a significant challenge.

Disclosure itself was experienced as stressful:

“I equate to some of my friends who are HIV-positive and feel they are all worried before they get that disclosure out of the way. It's even worse for me because they're not disclosing that, maybe, they won't be sexually functioning.” [MSU04]

“A lot of people hit on me, but I just dread that part in the conversation where I have to go, ‘Well, just so you know, I'm a survivor of prostate cancer and there's never going to be any cum.’” [MSU12]

A few men reported negative experiences with disclosure

“I met this guy and it was just a hookup. I got to his house and we started trying to play around, and nothing was happening, and I opened up when I started talking to him. Maybe it was too much information, I don't know, but he wouldn't even touch me after that. Freaked out, wouldn't touch me, and it was very clear that he wanted me to leave.” [MSU01]

Others reported disclosure led to successful or more satisfying encounters.

“I started having sex with people about six weeks after the surgery. It was all right, telling them the truth and whether they were still interested or not interested. [Once on a date] I told him that I was just recently started on Viagra and that my doctor had said he wanted to get some blood back into my penis. The guy I was talking to, said, ‘Can I help?’ A wonderful come on, it was funny and so appropriate. We had a very, very good time that night.” [MSU19]

(b) Effects on Relationships

Prostate surgery affects all aspects of GBM's lives, including their relationships. Men entering relationships describe the ED effects of surgery as a potential deal breaker. Men in relationships reported the sexual challenges as increasing relationship stress and likelihood of break-ups.

“Then we started dating. For a month or so, it was going really nicely, but about a month in he stopped in the middle of sex one night and he said, ‘I'm sorry, you're just not hard enough for me.’ I was really upset because I was developing feelings for him.” [MSU19]

“It's ruined my sex life and hurt my relationship. Doctors don't value the importance of sex in gay relationships” [MSU17]

Others framed the surgery as exacerbating pre-existing problems.

“I also was having troubles in my [same sex] marriage, as you can imagine. That fell apart. Sex was one of the main problems that was going on in the marriage that caused me to end it. I had a long sexless period when I was just masturbating because my partner withdrew from sex before me.” [MSU19]

For one respondent, whose relationship had ceased to be sexual, the sexual effects of prostate surgery worked to decrease the discrepant sexual interest in the relationship.

“We've been together for a little over 18 years. Like any other married couple, I guess, we just kind of redefined our relationship. We don't have sex anymore. We're very good friends and it works better that way. When we started out, I was always very sexual, he never was. So, most of our fights or arguments would have been about sex - my wanting it and he not wanting it. This worked out good for him because, now, he doesn't have to worry about having sex. It's an open relationship.” [MSU10]

For men currently involved in a relationship, the effect of surgery on their partner's sexual satisfaction was cited as a concern and an occasion to re-negotiate the sexual boundaries in the relationship.

“We're married now, and my husband is the best guy in the world. ... He's much younger than I am, and he's got a life to live. I know how important sex was in my life. I can't expect him to shrivel up and die just because I have. ... It's affected every part of our life, every part of it. I know he sees other people, and I can't blame him. We deal with it as best we can, but it's changed our relationship a hundred fold.” [MSU05]

Other men described the pain of wanting intimacy but not daring to place themselves in a relationship.

“[The biggest challenge is]... the lack of intimacy. I continue not wanting to put myself in a situation where there's rejection because of my disability. [MSU15]

At least, at least two respondents emphasized the powerfully healing effect of having an accepting partner.

“.... Once I found my [partner] and really found his reassurance and his support, I started to feel more a man again, more like a guy, more like I wasn't broken.” [MSU14]

Discussion

Given the lack of prior studies on this topic, the key finding of this study is that radical prostatectomy has major effects on GBM's emotional and mental health, on multiple aspects of sexual identity, and also on their same sex relationships. Emotionally, the almost universal initial response was shock, fear, and anxiety. In terms of mental health, participants described a period of “depression” lasting about a year and an ongoing situational anxiety, specific to having sex with a new partner and/or worrying whether a sexual event would be successful. Respondents identified changes in their sexual identities, specifically a decreased sense of maleness or masculinity, some a decreased sense of gayness or bisexuality, and especially for “top”-identified men, some change in role-in-sex identity. While some respondents reported these changes as mild and transient; most described the effects as permanent, and profoundly altering the shape of their sexual lives, identities, and relationships.

This paper confirms that several of the challenges reported by straight men and for heterosexual relationships are similar for GBM and in same sex relationships. While this is not surprising, documentation of these challenges is a helpful first step in confirming the effects of prostate cancer diagnosis and radical prostatectomy on GBM's lives and relationships.

We highlight three aspects of these findings that appear distinct from findings in the literature on heterosexual men with prostate cancer. First, the emotional-mental health challenges of our cohort of prostate cancer men may show a greater difficulty for GBM. GBM may experience greater emotional challenges because of the higher prevalence of baseline depression, anxiety and psychological distress in GBM compared to heterosexual men (Cochran et al., 2003); or because they have less familial (Kurdek, 2001, 2004a, 2004b, 2005; Smith et al., 2007) and social support (Kurdek, 2001, 2004b, 2005) (since support has been shown to be predictive of psychological distress in men undergoing prostate cancer treatment (Canada 2003). Alternatively, GBM may simply be more willing to admit to experiencing emotional challenges than their heterosexual counterparts (Cochran et al., 2003). And it could also be that sex may be more central to GBM's identity and lives making the emotional loss more profound. Whatever the underlying cause(s), what is clear is that the men in this study experienced significant emotional challenges during and after treatment. We note none reported their treatment as addressing these emotional aspects.

Second, the changes in role-in-sex identity appear a unique solution for (some) GBM, not available to heterosexual men. While many former "tops" reported experimenting with the bottom role to circumvent their ED challenges, some men appeared able to adjust their role, while others concluded it was impossible. Third, prostate cancer treatment has significant effects on same-sex relationships that appear handled in different ways from heterosexual relationships. In particular, participants discussed re-negotiating the exclusivity of the relationship (out of concern for their partner's sexual fulfillment).

While discussed as separate issues, many of these challenges are interconnected. When put together with the sexual challenges (see companion paper, this issue), an interesting picture emerges of the psychosexual challenges GBM face (see Figure 1). Immediately, post-surgery, GBM report a major change in anatomical functioning, which is accompanied by fairly immediate behavioral changes and expressed in on-going changes across all stages of the response cycle. Over the longer term, the participants talked about identity changes that may occur and vary by the participants' baseline identity. Changes in role in sex identity appear mainly driven by what the identity was before the operation and by the sexual behavior challenges, post-surgery. Other aspects of identity, such as decreased sense of being a man and diminished sense of being gay or bisexual, are likely driven by a combination of changes in anatomy, behavior, and sexual response. With the exception of shock and fear, which participants attributed to their initial diagnosis, depression, sex-specific situational anxiety, loss of spontaneity, and loss of sexual confidence were all described as emotional challenges stemming from the sexual effects of surgery. Similarly, the disclosure and relationship challenges were reported as stemming from the participants' functional sexual challenges.

There are several limitations to keep in mind in interpreting these results. First, self-report data are subject to such limitations as self-awareness, subjective interpretation, and self-censorship. Second, for the relationship data, we only interviewed the patient with prostate cancer. It is possible, or even likely, that partners have different perspectives that are important to capture. Third, this analysis is restricted to GBM who had radical prostatectomies. Generalizing from these results to other treatments or all GBM with prostate cancer is not valid. Fourth, the men in this study were recruited from a website offering social support. They may not be representative of all GBM with prostate cancer on such sites, or GBM who are not members of online support sites. Fifth, while the participants identified and discussed the emotional and mental health challenges following radical prostatectomy, in depth, the terms “emotional health” and “mental health” are used informally. No formal assessment or diagnosis was undertaken. Finally, while the sample had good age variability, geographic representation, and urban-rural representation, all but one man in this sample was white, gay-identified, and HIV negative. Because GBM of color, bisexual-identified men, and HIV positive men may face additional challenges, including stigma, it is important not to assume these findings generalize beyond white, HIV negative, gay-identified men.

Implications for Research, Policy, and Practice

These findings have important implications for treatment. Both on the ethical principle to “First, do no harm” and on the medical imperative to improve patient outcomes where possible, focusing rehabilitation on brief interventions to recover erectile performance and urinary continence appears insufficient to meet these men's needs. Almost all respondents described the treatment they experienced as limited to focus on erectile performance and heterocentric (meaning focused on restoring vaginal intercourse).

Developing culturally competent care for GBM with prostate cancer will require clinicians to appreciate the similarities and potential differences between GBM and heterosexual men that these results illustrate. In designing rehabilitation services for GBM following radical prostatectomy, it appears important to address the emotional and mental health sequelae of treatment, potential changes in identity, as well as its effects on same sex relationships. Given the lack of information on prostate cancer for GBM, sexual orientation specific educational materials are needed.

Clinicians can only provide evidenced-based care if the necessary research to inform practice is completed. In the area of GBM with prostate cancer, the literature is so thin that the necessary evidence is lacking. Future research directions include comparative studies of heterosexual and GBM to quantify and compare the effects of emotional distress, mental health, maleness/masculinity and sexual self-esteem. Longitudinal studies of GBM with prostate cancer are needed to confirm which emotional and mental health challenges reported in these results are transitory, long-lasting, and/or due to pre-existing elevated levels; whether the challenges differ by type of treatment, and to identify what cofactors moderate effects. Finally, we highlight the lack of studies on partners, and studies on same sex couples. Currently, this is an area where there are only two publications one, both case

reports, one of one couple and one of three couples. Only when such studies are undertaken will we have the empirical base to advance better treatment.

Conclusions

This is the first study to explore, in detail, the effects of radical prostatectomy on the mental health, identity, and relationships of GBM who have had radical prostatectomies. This study of 19 men who underwent radical prostatectomy confirms that GBM experience similar challenges to their heterosexual counterparts. Three potential differences were also identified. While prior research suggests GBM may experience greater emotional challenges and mental health problems following treatment, the results of this study illustrate five specific emotional-mental health challenges. While GBM report similar loss of masculinity and sexual self-esteem to heterosexual patients, change in role in sex and possibly a weakening in gay/bi identity are additional identity challenges for GBM, not experienced by heterosexual men. Some GBM report being able to make adjustments in their role-in-sex identity, while others report such adjustments are impossible. And while both GBM and heterosexual men with prostate cancer describe prostate cancer as affecting their long-term relationships, GBM report re-negotiating the exclusivity of their relationship in order to address their partners' sexual needs.

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Biography

Dr. B. R. Simon Rosser is a psychologist, epidemiologist and clinical/research sexologist specializing in GBM's sexual health. His background in studying GBM sexual dysfunction, sex between men, physician-GBM patient communication, mental health, Internet methods, sex measure development, evaluation of sexual health interventions, human subjects and in leading NIH behavioral trials.

Dr. Benjamin Capistrant is an Assistant Professor at the University of Minnesota and a member of the Minnesota Population Center. His research focuses on social determinants of aging and non-communicable diseases, both in the U.S., and in low and middle income countries. He is particularly interested in the interplay between family dynamics and health in old age. He completed his Masters and Doctoral training in social epidemiology at Harvard University and postdoctoral training in population aging at University of North Carolina - Chapel Hill.

Dr. Beatriz Torres is an Associate professor of Communication Studies and was awarded Mexico's National Council of Science and Technology and Fulbright scholarships. She consults and trains health care organizations on effective cross-cultural communication. Her scholarship looks at the intersection between culture and health communication. She is involved in several community based participatory action research projects developing entertainment education media to promote the health of Latino, Hmong and Somali immigrants in Minnesota.

Dr. Badrinath Konety is a prostate cancer specialist who leads the biomedical and oncological aspects of the study

Dr. Merengwa is a Physician-Scientist and a cancer health disparities epidemiologist at the University of Minnesota. He has earned a Medical Degree (MD), Master of Public Health (MPH) degree in Epidemiology and currently enrolled in a Doctor of Public Health (DrPH) degree program

Mr. Darryl Mitteldorf wrote some of the first clinical articles of GBM with PCa and founded *Malecare*, the largest organization serving GBM with PCa. A community-based collaborator, he will lead recruitment, attend meetings by Skype, and participate in the write up of results.

Mr. William West is an online communications specialist who will design the interactive, online curriculum for GBM with PCa. As an out GBM with PCa, he will also serve as our participants' advocate.

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Figure 1.
Visual Schematic of the Psychosexual Effects of Radical Prostatectomy on Gay and Bisexual Men
(N = 19 indepth qualitative interviews)