

PAPER

Caregiving and social support for gay and bisexual men with prostate cancer

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Abstract

Objective Prostate cancer, the second most common cancer among men, typically onsets in middle or older age. Gay/bisexual men have different social networks and unique social support needs, particularly as it pertains to health care access and prostate side effects. Few studies have investigated the availability and provision of social support for gay and bisexual men with prostate cancer (GBMPCa).

Methods This study used qualitative data from in-depth, semistructured, one-on-one telephone interviews with 30 GBMPCa recruited from a national cancer support group network, Malecare. Inductive and deductive codes were used to identify themes about social support provided to GBMPCa during diagnosis and treatment.

Results GBMPCa reported help from friends, family (parents and siblings), ex-partners, and paid caregivers. Men in relationships reported varying levels of reliance on their partners for support, in part due to relationship dynamics and living arrangements. Single men showed a theme of independence (“I turned down all help,” “My friends don’t want to be bothered”). After diagnosis, many men reported seeking informational and emotional support from prostate cancer support groups; most expressed wanting more support groups specifically for GBMPCa. During or after treatment, men reported receiving a range of instrumental support, largely a function of relationship status and treatment type.

Conclusions GBMPCa received variable, but generally low, social support during diagnosis and treatment and from a diverse social network, including a prominence of friends and family. Clinicians should be aware of GBMPCa’s distinct patterns of social support needs and providers.

KEYWORDS

caregiving, homosexuality, oncology nursing, prostate cancer, qualitative research, social support

1 | BACKGROUND

Prostate cancer (PCa) is the second most common cancer among men,¹ and like other cancers, it typically requires extensive social support.^{2–5} Gay and bisexual men with PCa (GBMPCa) have unique social networks and support needs.^{6–8} Gay men are less likely to be married and, thus, have spouses or to have children,⁹ and they are 1 of the 2 most common caregivers to middle- and older-aged men.^{10,11} Instead, LGBT people rely on friends or “chosen” families rather than biological or given families from whom they may be estranged.^{12,13} Gay and bisexual men may need different social support, including

informational support such as referrals to gay-friendly doctors and emotional support about erectile dysfunction or prostate sensitivity, given the more prominent role anal sex plays in gay men’s sex lives. Lower social support can contribute to worse PCa outcomes (ie, less instrumental support/caregiving),^{14,15} and differences in social support may contribute to disparities in outcomes between gay and bisexual men compared with straight men.¹⁶

Types of social support needs may vary across by time and treatment type. In addition to instrumental support or direct caregiving, other domains of social support^{17–20}—informational, appraisal, and emotional social support¹⁸—are also crucial for men with PCa.²¹ For

example, men undergoing radical prostatectomy may need more direct caregiving than men getting radiation treatment, and men with more side effects of treatment may need more emotional support than those with fewer side effects. Moreover, instrumental/caregiving care may be more necessary during treatment than at the time of diagnosis; other kinds of support may be constant or vary across this diagnosis-through-treatment timeline.

Thus, GBMPCa have unique social support needs and social network compositions, which inform the kinds of assistance offered and needed.²²⁻²⁴ However, to the best of our review,²⁵ no studies have investigated the role of social support for GBMPCa specifically. To address this gap in research on social support for GBMPCa, this study collected and analyzed qualitative data from in-depth, semistructured interviews with GBMPCa to investigate the kinds of social support men received, as well as reported needing/wanting but not receiving, throughout PCa diagnosis and treatment.

2 | METHODS

This study used a qualitative design—specifically, one-on-one telephone interviews—and was oriented by a thematic analysis.²⁶ The study was approved by the University of Minnesota Institutional Review Board (1408S52902).

2.1 | Study participants and recruitment

Participants for the study were recruited from Malecare, the largest men's cancer support group and advocacy organization in the United States. Malecare facilitates both in-person and online support groups, including online support groups for GBMPCa and specific groups for

GBM facing urinary and sexual dysfunction problems (ie, the most common side effects of treatment). The study was introduced to all Malecare members via e-mail and via the Malecare e-newsletter, which included a link to the study's website where participants were screened for eligibility. The study population is adult (18 years and older), English-speaking GBM treated for PCa living in the United States. Those undergoing watchful waiting or had completed treatment less than 6 months before eligibility screening were ineligible. Those interested and eligible completed an online informed consent process and scheduled a time for a one-on-one telephone interview. Participants were compensated \$35 for their time.

The study used a stratified sampling approach for GBMPCa. The sample was stratified *a priori*—radical prostatectomy surgery, radiation therapy, and any other treatment (eg, multiple treatment types, hormone therapy, and chemotherapy)—to gather sufficient depth of experience across 3 common PCa treatment types. The recruitment of the sample was by convenience (ie, those who responded directly from the study announcements in Malecare communications). Participant characteristics are presented in Tables 1 and 2.

2.2 | Data collection

After a series of demographic questions collected by online survey, the semistructured interviews covered several domains along the timeline of diagnosis, treatment, and rehabilitation. Throughout these temporal anchors, GBMPCa were asked to discuss their experiences with PCa, particularly their experience with providers, health, sexual functioning, and relationships throughout their experience of PCa. Of particular relevance for this analysis, the interviewer probed about different domains of social support—informational, instrumental, emotional—as well as asked about what kinds of needs, including support, they would

TABLE 1 Demographic sample characteristics of GBMPCa by treatment type: the restore study

No. Men	Radical prostatectomy		Radiation		Other treatment	
	n/mean	19 %/SD	n/mean	6 %/SD	n/mean	5 %/SD
Age, y	62.4	6.7	69.2	5.5	63.0	4.4
Sexual identification						
Gay	18	95%	6	100%	4	80%
Bisexual	1	5%	0	0%	1	20%
Race/ethnicity						
Non-Hispanic white	18	95%	5	83%	3	60%
Non-Hispanic black	1	5%	1	17%	1	20%
Hispanic white	0	0%	0	0%	1	20%
HIV status						
HIV positive	0	0%	1	17%	1	20%
HIV negative	18	95%	5	83%	4	80%
Unsure	1	5%	0	0%	0	0%
US Census region						
West	2	11%	2	33%	1	20%
Midwest	7	37%	1	17%	1	20%
South	4	21%	1	17%	3	60%
Northeast	6	32%	2	33%	0	0%
Years since PCa diagnosis	7.0	3.1	9.7	11.4	6.0	4.6

TABLE 2 Demographic characteristics of GBMPCa quoted in text

Pseudonym	Age	Treatment type	Sexual identification	Race/ethnicity	Years since diagnosis
William	67	Other	Gay	Non-Hispanic white	3
Richard	63	Other	Gay	Non-Hispanic black	1
Thomas	67	Other	Bisexual	Non-Hispanic white	3
James	74	Radiation	Gay	Non-Hispanic white	11
Michael	69	Radiation	Gay	Non-Hispanic white	2
Robert	64	Radiation	Gay	Non-Hispanic white	3
John	61	Radiation	Gay	Non-Hispanic white	1
Mark	57	Surgery	Gay	Non-Hispanic black	10
Charles	67	Surgery	Gay	Non-Hispanic white	8
Steven	48	Surgery	Gay	Non-Hispanic white	5
Paul	66	Surgery	Gay	Non-Hispanic white	3
Larry	72	Surgery	Gay	Non-Hispanic white	7
Gary	63	Surgery	Gay	Non-Hispanic white	7
Joseph	55	Surgery	Gay	Non-Hispanic white	3
Donald	63	Surgery	Gay	Non-Hispanic white	7
Ronald	52	Surgery	Gay	Non-Hispanic white	11
Kenneth	61	Surgery	Gay	Non-Hispanic white	5
Daniel	70	Surgery	Gay	Non-Hispanic white	2

have wanted. The interviews, which lasted between 60 and 90 min, were conducted between March and July 2015. Investigators considered theoretical saturation²⁷—when new data yielded neither additional concepts nor further insights into existing categories—throughout data collection, and study recruitment ended when they determined sufficient saturation had been reached.

2.3 | Data analysis

Data analysis was informed by thematic analysis approaches.²⁶ Inductive and deductive codes were applied based on the structure of the interview guide and common conceptual frameworks of social support to organize and maximize implications for future research and practice; emic themes that emerged from the data. The codes were then grouped into hierarchical categories as a means of organizing the coded data. The clustering and organization of these data was conducted in Microsoft Excel by 1 investigator (author 2) in discussion with another investigator (author 1). For this particular analysis, a hybrid approach of an *emic* process of coding new themes and an *etic* process of applying established social support framework¹⁸ to further organize themes was used. Specifically, this social support framework articulates 4 domains of social support: instrumental (eg, direct ctangible help and assistance, like caregiving; in-kind or financial), informational (eg, advice or education about a particular topic), appraisal (eg, help in decision making, including feedback that guides which course of action to take), and emotional (eg, love, sympathy, and understanding). The process of integrating emic and etic codes was primarily led by a separate investigator (author 1), with insights and input both from the rest of the investigator team, including the investigator who lead the coding/categorization. Themes and illustrative quotes are presented in the text as well as summarized in Table 3.

3 | RESULTS

3.1 | Participants

There were 30 total interviews with GBMPCa whose data were used in this analysis. Most ($n = 19$, or 63%) had radical prostatectomy csurgery (“Surgery” in the text), 6 (20%) had radiation therapy (“Radiation”), and 5 (17%) had some other treatment (“Other”). In this sample, “other” treatments also included multiple treatments. Participants were primarily of white race. Demographic characteristics of the total sample are presented in Table 1 and of those men quoted in Table 2.

3.2 | Social support across the treatment timeline

3.2.1 | Unmet needs

Several men who did not have access to a gay support group, locally, reported wanting it. “Well, I asked the doctor at that point if there was a local support group for gay men with PCa and there wasn’t. That would be I would think an asset” (Larry/72/Surgery). Others shared the sentiment of wishing they could have in-person support groups with gay men.

“I was going to add ... the gay support groups that I’m part of online. I find that, life sucks sometimes but if you can at least share that, you’d feel so much better if you can share. ... If every major city have gay group or any kind of group that just talk about male sexuality after surgery would be really good.” (Joseph/55/Surgery).

“I just said to the social worker, “How many gay men do you have who have prostate cancer.” She’s goes, “I don’t really know because they don’t tell us.” “Could we start a group for men, gay men?” She said sure but she didn’t know how to start even. I still think

TABLE 3 Summary of social support both received and not-received and the role of social network to provide support across the treatment timeline

Received/ not-received	Treatment timeline	Support	Network	
			Members	Roles
Received				
	Throughout	Instrumental, emotional	Partners, friends, family, support groups	Friends and partners attended doctor's appointments; emotional support throughout
	Before treatment	Instrumental, emotional, informational, appraisal	Partners, friends, family, support groups	Partners played varied roles in terms of appraisal support for treatment decision making; support groups offered informational/appraisal support to inform decision making
	During treatment	Instrumental	Partners (if available), friends, family, paid caregivers	Family members (parents/siblings) helped around surgery; 1 or 2 days after surgery; partners played varied role by treatment type (less intensive for radiation than surgery)
	After treatment	Informational, emotional	Partners, friends, support groups	Offering informational and emotional support for treatment side effects
Wanted/unmet support or done by self				
	Throughout	Informational/emotional/appraisal	GBMPCa support groups	
	Before treatment			
	During treatment	Instrumental support/caregiving postsurgery	Done alone	Not wanting to ask for instrumental support from friends because of catheter
	After treatment	Informational, emotional	Partners, friends, support groups	Some noted being very selective about who could provide support about treatment side effects

about would it have been nice to be able to be in a room with guys should be able to talk like this like I'm talking to you." (Paul/66/Surgery).

Although not all men stated explicitly why they wanted a gay-specific support group, those who did expressed the sentiment of being more at ease when talking with other gay men.

"I know some people had talked about how important it is to have a support group and if you go to a typical prostate support group it's all straight men and it's usually it's their wives that are talking." (Daniel/70/Surgery).

"It's horrifying because there's this old man talking about sex with the wife. They don't want to hear about my problem. I didn't want to hear about theirs. It didn't work for me." (Paul/66/Surgery).

3.2.2 | Instrumental support

One form of instrumental support men reported throughout the treatment and survivorship timeline was having people attend appointments with them.

"Somebody said, 'Get somebody to go with you on Monday to the Urologist. It's very hard for you as the

one in the cross-hairs to really understand what all these people are talking about. Bring somebody, have them bring a notepad and have him ask questions too and at the very least just take notes and jot this down so you can sort it all out.'" (John/ 61/Radiation).

3.3 | Social support before beginning treatment

3.3.1 | Informational/appraisal support

Much of the social support GBMPCa reported during diagnosis was a combination of informational and appraisal support¹⁸ to understand PCa, treatment options, and treatment side effects to inform their own treatment decisions. Men sought out social support groups to find information about possible treatments and side effects because they wanted to hear directly from first hand experiences, and to aid in their own decision-making process regarding treatment. Many men mentioned going to support groups for gay men; however, not all mention explicitly the sexual orientation parameters of the group.

Several men reported engaging with both online and in-person support groups during this phase of their PCa experience. Many of them reported receiving informational support about different treatment types and their side effects.

"I decided that I didn't want to go through the incontinence and all of the surrounding stuff with the surgery ... probably 80 percent of the guys in the [Malecare] support group over at [LGBT] Center have had either SBRT [stereotactic body radiation therapy] or CyberKnife [robotic-assisted radiation therapy], so it was a comfort level [to choose radiation treatments]." (Michael, 69/Radiation).

"My urologist [s patient] told me about a support group here in the city for gay men with prostate cancer. I joined immediately and I learned most of what I know from them ... the group was full of information." (Ronald/52/Surgery).

3.3.2 | Emotional/informational

Some men also reported talking with people in their support network, mostly friends, during this phase of their PCa treatment. Some of this was emotional support, whereas for other men this was specifically informational and instrumental, as they were talking with others who had experience with PCa.

"I know I did a little bit of research, but not that much. I'm part of this Yahoo group [Malecare] now that talks a lot more about second opinions and doing research and stuff, but what I did is I talked to a good friend of mine." (Joseph/55/Surgery).

"I had one very good friend who had just finished going through it. He was very helpful. He and I had a lot of good talks when [his partner] wasn't around and my partner wasn't around." (William/67/Other).

3.3.3 | Social network for support before treatment

Help from others in their social networks ranged from very involved to uninvolved. Notably, those men in relationships reported a range of involvement in treatment decision making (ie, appraisal support) from their partners. Some men reported that their partners were not really involved in making these treatment decisions: "Not very much. As far as trying to decide what to do, he really wasn't too involved" (Robert/64/Radiation). However, others reported quite the opposite: "We would be able to sit and go through stuff and decide together" (William/67/Other).

3.4 | Social support during treatment

3.4.1 | Instrumental support

During treatment, men undertaking radiation and other treatments reported little instrumental support compared with men undergoing surgery. Most of the instrumental support came in the form of rides to/from appointments. Notably, several men undertaking radiation and other treatments took themselves to treatment appointments. Indeed, there was a theme of independence that emerged mostly from the men with radiation and other treatments about the kinds of support they had during treatment.

"I think I just took the bus to the hospital on my own. Coming home from the hospital, I just had a friend come and accompany me in the taxi to come home. I live alone but I didn't feel any need to have any heavy services to take care of me." (James/74/Radiation).

"[We are] very close, [my partners is] very supportive, all the right stuff, but I'm fairly independent when it comes to that. I'd drive up every morning at 9 am, get off the table around 10:15 and drive myself home. Five days. No, [he was] very, very supportive, but I'm my own man when it comes to [that]." (Michael/69/Radiation).

In contrast to the men who undertook radiation and other therapies, men who had radical prostatectomies reported needing and receiving more instrumental support immediately before and especially in the first days to weeks after returning home from surgery, such as cooking food, running errands, transportation, and cleaning wounds.

"Shortly after surgery. I was lucky I had a sister who was a nurse who came to stay with me for a few days and we talked quite a bit about it. I got to know what's going on and what's going to happen." (Charles/67/Surgery).

"My mom ... drove down from [other large Midwestern city] on the day of the surgery." (Donald/63/Surgery).

"[A close friend] had a key to the apartment. He would come over at will. He would even come over in the middle of the night to make sure I was okay." (Kenneth/61/Surgery).

3.4.2 | Support network for instrumental support

Most of the partnered men who had surgery got instrumental caregiving from their partners.

"Had it not been for my partner, who would have gone to the hospital with me? I've got a couple of friends who would have done it, but could I really ask them, would you please carefully put my urine bag on that piece of the bed that runs along its side?" (Paul/66/Surgery).

Indeed, GBMPCa raised having a catheter in as a barrier that impeded asking for instrumental support after surgery.

"I was alone to recover. ... I didn't really want a lot of company. I mean, I'm walking around the house with a catheter tube sticking out of me, it wasn't really the time." (Steven/48/Surgery).

Another predominant theme, particularly among single men, was of independence or being solitary. This independence theme referred to

people either not asking for or turning down help, whereas being solitary reflected more comprehensive social isolation. Several men with surgery reported simply being home alone; most were not explicit about whether they needed more support than what they were getting.

"A cousin of mine [came with me to the surgery]. I live alone and when I came home, the first day that I was there, my best friend and a couple of other friends came over and made sure that I was comfortable and situated in the house. After that and from that point on, I just did it myself." (Mark/57/Surgery).

"I'm single. My family is in [Midwestern state], so my brother came down, which was nice, for the day of surgery, but my good friend just basically dropped me off at the hospital. Then for the rest of the week, I was by myself." (Joseph/55/Surgery).

This is in contrast to the tone among men who had radiation and those who underwent other treatments. Both groups either had support available but reported not needing it or felt like support was unavailable and seeking support from outside their family.

"There was [help] during that initial time, yes. My big brother ... helped me out some. ... Since then I've had no other caretakers. I had pretty much done everything on my own." (Robert/64/Radiation).

"I have no close family at all. My friends don't want to be bothered. They don't want to hear about it. I have a paid caregiver who comes in four days a week, four and a half hours a day." (Thomas, 67/Other).

Notably, the instrumental support single GBMPCa did receive came largely from friends, family and paid caregivers.

3.4.3 | Emotional support

Emotional support represented the next most common component of social support during treatment. Many men, across the different treatment types, spoke generally of having people who came to visit/spend time with them, to check on them, or noted people whom they enjoyed talking to.

"I basically lived in a particular neighborhood and I had friends from a particular bar, actually, and we all became social friends outside of that place, and they were all there for me. Some of them live in that building, some of them just live nearby..." (Donald/63/Surgery).

3.5 | Social support after treatment

3.5.1 | Informational/emotional support

After treatment, the primary type of support men reported was informational and emotional support about sexual rehabilitation. Other men mentioned a transition from needing and using support—informational

and emotional—to providing this support by remaining active in PCA support groups.

"Being the age that I am, I think all I would ask for in the future is what we can do for our younger brothers who are just experiencing this for the first time, and allowing them to have someone to talk to, or someone to depend on, or to learn from. I'm about giving back." (Richard/63/Other).

3.5.2 | Support network for support after treatment

For the support GBMPCa needed after treatment, men were selective as to whom they talked to regarding sexual side effects. Some confided in partners, others to friends or other social support groups, but generally less on family. A distinct minority of men noted helpful friends and sympathetic partners.

"Afterward, when I realized even with injections and treatments that were there, 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." (Gary/63/Surgery).

4 | DISCUSSION

In this qualitative study of 30 GBMPCa, there are 2 key results. First, GBMPCa's social support networks appear notably different from the dominant literature on men with PCA. GBMPCa expressed either wanting or using a GBMPCa-specific support group. GBMPCa's partners played varied roles for social support. Many men, especially single men, reported not having much instrumental support throughout recovery. Of those who had support, their social support network consisted largely of friends, parents, and siblings. Second, the social support GBMPCa report receiving varied across the domain of social support and differed between the time of diagnosis and during treatment.

4.1 | Strengths and weaknesses

Although our goal was not to sample stratified by race or sexual orientation, we caution saturation was not reached across race or sexual orientation and have not made explicit comparisons of differences in by these factors. Moreover, we note that our study design does not facilitate direct comparisons to the dominant literature of men in heterosexual relationships; however, we speculate and show how our work fits within the findings of this previous work. We did not consistently capture detailed information on participants' relationship status (ie, monogamous, duration) or their partners' gender. We caution their experience may not reflect other GBMPCa's experience who have not sought online support. The "other treatment" group comprised both men who had less common treatments and men whose advanced

cancer treatment meant they had treatments in addition to surgery or radiation. Not all interviews explored the experiences of social support to the same depth, which resulted in some sparsity in the data; this is particularly true of emotional support, as that domain was not explicitly focused on in interviews. Moreover, some of the respondents' responses were more straightforwardly descriptive and lacked nuanced emotional content; this might have been a result of our attention to a wider scope of issues in the interview other than just social support or of mainstream masculinity. Phone interviews also may have limited the emotional depth of the interview compared with in-person interviews where establishing rapport is easier. We recruited from 1 online forum; results may have differed if recruitment were in person or from multiple online venues.

These weaknesses notwithstanding, this study has many strengths. As the first published study of support persons, it breaks new ground. With 30 interviews, it is the largest qualitative study of social support for GBMPCa to date, and the first with sufficient subgroups of men who underwent surgery, radiation, or other treatment to enable comparative analysis.

4.2 | Comparison to prior literature

Our findings clearly articulate how GBMPCa's social network influences availability and receipt of social support. The provision of support by parents, siblings, and friends contrasted with the existing literature of social support for men with PCa. Much of the qualitative studies of support for men with PCa focus on spouses, the vast majority of whom are wives.⁵ Notably, partners in this sample played quite varied roles for appraisal support at diagnosis and instrumental support through treatment; this contrasts with literature from wives of men with PCa who are more consistently involved throughout the treatment process. In contrast to the dominant literature, only 1 mentioned adult children. These findings also highlight the unique role friends—sometimes conceptualized as “chosen family”—can and do play in gay, bi, lesbian, and transgender (LGBT) social networks.^{28–34} Many men mentioned wanting a specific group for GBMPCa where they felt more shared experiences with the other members of the group. This might reflect gaps in the men's social network with respect to informational or emotional support specific to PCa.

We speculate that this different support structure has both strengths and weaknesses for GBMPCa. GBMPCa reported feeling free to talk about the sexual and continence challenges with their friends (in a way they reported not sharing with family). On the other hand, many men, especially single men, reported that the catheter postsurgery meant they were less willing to get support and preferred to “tough it out” alone. It is possible that GBMPCa's different social network composition combined with mainstream social constructions of masculinity resulted in lower comfort asking for help from those around.

The experience of GBMPCa fit well within the dominant paradigms of social support domains.^{18,19,35} For example, our results showed that the social support many men sought after diagnosis and before treatment was largely informational; moreover, true to the original definitions of informational support, it was indeed information for the purposes of decision making.

4.3 | Implications for future research, policy, and practice

Additional support resources tailored for and directed to GBMPCa seem highly relevant and in high demand. In particular for this analysis, the expressed wish for or use of support groups (ideally in person) for other gay men with PCa was noted. Clinicians treating GBMPCa should consider referral to local groups where available and/or to online groups to meet this need. Clinicians should take into account the more varied support network GBMPCa may have, specifically the central role of friends and other family. Future work with spouses/partners of GBMPCa is warranted, should consider the variation in the partners' role(s), and should examine how it may be related to patient outcomes. An avenue for future research would be to test how social support is associated with differences in PCa outcomes between GBMPCa and other men.

4.4 | Conclusions

This is the first study of social support needs among GBMPCa. Our results suggest the amount and kind of social support GBMPCa need varies across the PCa timeline, by treatment, and is provided substantially from friends and family rather than partners/spouses and offspring, or it goes unmet. These data present a rich narrative of the myriad supports that gay/bi men with PCa need and sometimes get. Additional qualitative and quantitative research is needed on PCa in gay and bisexual men. Such research needs to conceptualize social support networks broadly and inclusively and should focus on the relationship between social support and patient outcomes.

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