

# Hidden Patients, Hidden Partners: Prostate Cancer Care for Gay and Bisexual Men

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Research and clinical practice efforts to improve outcomes for men with prostate cancer have largely ignored the unique social support circumstances of gay and bisexual men (GBM), leading to a gap in the literature regarding social support needs of GBM with prostate cancer. Capistrant et al. (2018) addressed this gap by using survey data to examine social support and quality of life in GBM with prostate cancer. Their work provides insights about how nurses can make changes through research and clinical care to better treat GBM with prostate cancer.

Men treated for prostate cancer often experience disease- and treatment-related sequelae that negatively affect their quality of life, mental health, and sexual function (Ussher et al., 2016). Social support buffers this effect for many men (Mehnert, Lehmann, Graefen, Huland, & Koch, 2010). However, research and clinical practice efforts to improve outcomes for men with prostate cancer have largely ignored the unique social support circumstances of gay and bisexual men (GBM) (Capistrant et al., 2016; Hoyt et al., 2017). Capistrant et al. (2018) addressed this gap by using survey data to examine social support and quality of life in GBM with prostate cancer. Their study highlights several pressing issues confronting GBM and can potentially be generalized regarding the needs of sexual and gender minority (SGM) patients with cancer.

SGM individuals may be at higher risk for cancer, engage in more health risk behaviors postcancer, have less access to care, and experience worse cancer-related outcomes than their heterosexual and cisgender counterparts (those who partner with members of the opposite sex and whose sex assigned at birth matches their gender identity, respectively) (Choi & Meyer, 2016). Studies of GBM with prostate cancer, specifically, highlight that GBM report worse quality of life,

worse satisfaction with treatment, and worse psychological and cancer-related distress after treatment than heterosexual men (Ussher et al., 2016). To compound this problem, clinicians may not competently facilitate disclosure of SGM identity; nondisclosure has been linked to poor satisfaction with care and health outcomes (Durso & Meyer, 2013). Caregivers and support partners of GBM with cancer are often not acknowledged and are rendered invisible in care (Bare, Margolies, & Boehmer, 2014), which has led to a population of hidden patients and partners.

Capistrant et al. (2018) have taken a first step toward making these patients and their support networks visible. As their study highlights, social support may look different for GBM with prostate cancer compared to heterosexual men. Although 46% of GBM in the study's sample had a spouse/partner who was involved in their care, many GBM are single and/or do not have children (Capistrant et al., 2018). In addition, social support for GBM is less likely to come from biologic family because of lack of acceptance; therefore, many find support from chosen family instead. Chosen family refers to a network of friends who provide social support. According to the study, 40% of respondents reported receiving support from chosen family, but only 34% reported receiving support from biologic family members.

Chosen family and non-marital caregivers are often not acknowledged in healthcare settings or not treated as equal participants in medical decision making (Kamen, 2018). Chosen family caregivers are not biologically related or necessarily married to the patient; if these caregivers are also SGM, they may have

**KEYWORDS** prostate cancer; gay and bisexual men; homosexuality; social support; sexual minority

**ONF, 45(4), 435–438.**

**DOI** 10.1188/18.ONF.435-438

experienced previous discrimination by healthcare providers and may be less likely to have a spouse, partner, or children (Pew Research Center, 2013). This can lead to less social support to buffer caregiver burden and stress (Shiu, Muraco, & Fredriksen-Goldsen, 2016). In the specific context of cancer, these caregivers may not feel comfortable accessing resources available to the caregivers of heterosexual and cisgender patients (Burkhalter et al., 2016; Kamen, Smith-Stoner, Heckler, Flannery, & Margolies, 2015). The Capistrant et al. (2018) article underscores the diversity of support networks accessed by GBM patients with cancer—and SGM patients more broadly—but more work is needed to ensure that healthcare settings are responsive to these caregivers' needs.

GBM treated for prostate cancer report worse sexual quality of life than their heterosexual counterparts. The physical sequelae of prostate cancer treatment often have different meaning for GBM in relation to their sexual role, function, and identity. Treatment for prostate cancer can cause loss of libido, loss of ejaculate, climacturia, rectal irritation or pain, loss of prostate as site of sexual pleasure in anal sex, reduced penis size, and erections too weak for insertive sex (Ussher et al., 2016, 2017). Although treatment-related effects can negatively affect all sexually active men, these effects often have particular significance for GBM related to gay sex and gay identities and can lead to feelings of exclusion from a sexual community that is important to many GBM (Ussher et al., 2017). For example, erectile dysfunction in GBM treated for prostate cancer has been associated with emotional distress, negative impact on gay identity, and feelings of sexual disqualification (Ussher et al., 2017). Researchers and clinicians should be aware of the meaning and consequences of sexual dysfunction in GBM treated for prostate cancer and whether the effect includes social and/or sexual isolation.

Although quality of life is important on its own, considerable evidence exists that quality of life confers a survival benefit for cancer survivors as well. In repeated studies among patients with various types of cancer, high quality of life was predictive of survival postcancer even when controlling for disease and treatment factors (Montazeri, 2009). Because issues related to SGM patients with cancer are understudied, it is unclear whether these same survival benefits are seen in this population. However, theorizing that those benefits exist indicates the importance of assessing and addressing disparities in quality of life that may affect GBM.

In the Capistrant et al. (2018) study, GBM with prostate cancer who received more types of support

(e.g., emotional support, informational support, activities of daily living, medical appointment support) and had a broader, more diverse social support network had higher quality of life. However, the advantage of a broader social network held true only for sexual and physical quality-of-life measures. These study results reinforce existing research showing the value of a large social support network for SGM survivors, as well as the diversity of these networks (Capistrant et al., 2016; Erosheva, Kim, Emler, & Fredriksen-Goldsen, 2016; Kim, Fredriksen-Goldsen, Bryan, & Muraco, 2017). It is unclear, however, whether the impact of these social networks is felt across multiple domains of quality of life for SGM survivors or whether the effect is limited, as was shown for GBM. Also unclear is the primacy of sexual and physical quality of life for other SGM communities, including lesbian and transgender patients with cancer.

The study by Capistrant et al. (2018) has some limitations that affect interpretation of results. The authors dichotomized relationship status as those currently in a relationship versus those not in relationships, but substantial evidence shows that outcomes differ for individuals in different relationship configurations (Goldsen et al., 2017; Kamen, Mustian, et al., 2015). For example, Aizer et al. (2013) showed that marriage confers a substantial survival benefit for presumably heterosexual patients. Whether this benefit extends to same-sex couples who have sought legal marriage; those who are in long-term, marriage-like relationships; and those who are dating more casually is unknown. The sample of GBM with prostate cancer in the Capistrant et al. (2018) study is highly educated, with more than 77% of respondents having a bachelor's degree or higher, and may not represent the broader population of GBM with prostate cancer.

Describing the experiences and unique needs of GBM with cancer is an important first step; however, changes must now be made through research and clinical care to better treat GBM and all SGM people with cancer (Rice & Schabath, 2018). The need for valid and reliable tools to measure relationship type and quality, social support networks, and sexual well-being outcomes in SGM people has been identified (Gabrielson, Holston, & Dyck, 2014). This need must be balanced with the importance of using available resources and interventions. Questions remain regarding the effect of social support status, sexual outcomes, and financial toxicity on treatment decisions. To aid in answering these questions, funding opportunities in the area of SGM and cancer exist, including a funding opportunity

from the National Institutes of Health titled the Health of SGM Populations.

Prostate cancer is a disease of aging, and GBM with prostate cancer are part of the outpouring of older cancer survivors whose needs will outstrip the services and resources of the existing oncology healthcare structure (Bluethmann, Mariotto, & Rowland, 2016). The number of older survivors identifying as SGM more broadly will more than double by 2030 (Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emler, 2015), and they may face barriers to receiving formal health care because of fear of discrimination and may accumulate a greater financial strain from a lifetime of disparities in earnings, employment, and access to legal and social programs compared to non-SGM peers (Choi & Meyer, 2016). A need exists for policy addressing antidiscrimination legislation, expanding the definition of family to include chosen family, and recognizing SGM older adults as a group of greatest social need by the Older Americans Act to prioritize funding for research and social services. Clinically, a need exists for culturally sensitive training for healthcare and social service providers to support SGM older adults with cancer. Through research, policy, and practice, nurses can play a pivotal role in increasing the quality of care for GBM with prostate cancer and other SGM patients.

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No financial relationships to disclose.

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