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

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Abstract

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). Caregivers and support partners of GBM patients are often not acknowledged and are rendered invisible in care. This has led to a population of hidden patients, as well as hidden caregivers and partners. Capistrant and colleagues (2018) have addressed this gap by conducting the largest survey to date of 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 and, by extension, all SGM people with cancer.

Men treated for prostate cancer often experience disease- and treatment-related sequelae that negatively impact their quality of life, mental health, and sexual function (Ussher et al., 2016). Social support buffers this impact 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 and colleagues (2018) have addressed this gap by conducting the largest survey to date of social support and quality of life in GBM with prostate cancer. This study highlights several pressing issues confronting GBM, and can also speak to the needs of sexual and gender minority (SGM) cancer patients in general.

SGM individuals may be at higher risk for cancer, engage in more health risk behaviors post-cancer, have less access to care, and experience worse cancer-related outcomes than their heterosexual and cisgender counterparts (i.e., those who partner with members of the opposite sex and whose sex assigned at birth matches their gender identity; 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; non-disclosure has been linked to poor satisfaction with care and health outcomes (Durso & Meyer, 2013). Caregivers and support partners of GBM patients are often not acknowledged

and are rendered invisible in care (Bare, Margolies, & Boehmer, 2014). This has led to a population of hidden patients, as well as hidden caregivers and partners.

Capistrant and colleagues (2018) have taken a first step toward making these patients visible. As their study highlights, social support may look very different for GBM with prostate cancer compared to heterosexual men. For example, while 46% of GBM in this study's sample had a spouse/partner who was involved in their care (Capistrant et al., 2018), many GBM are single and many do not have children, relative to samples of heterosexual men. In addition, social support for GBM is less likely to come from biological family due to lack of acceptance, and therefore many find support instead from chosen family. Chosen family, an important construct highlighted by the Capistrant et al. article, refers to a network of friends who provide social support. Capistrant et al. noted that 62.3% of respondents report receiving support from chosen family or a friend, while only 33.9% report receiving social support from biological family members.

Unfortunately, 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). If these caregivers are themselves SGM, they may have experienced previous discrimination by healthcare providers. They may also be less likely to have a spouse, partner or children ("A Survey of LGBT Americans," 2013), and may also have less social support to fall back on to buffer caregiver burden/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. article underscores the diversity of support networks accessed by GBM cancer patients, and SGM patients more broadly, but more work is needed to ensure that healthcare settings are responsive to these caregivers' needs.

In terms of outcomes, the Capistrant article finds that GBM treated for prostate cancer report worse sexual QOL 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). While these treatment-related effects can negatively impact all sexually active men, these effects often have particular significance for GBM with regards to gay sex and gay identities, leading 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.

While QOL is of importance in its own right, there is also considerable evidence that QOL confers a survival benefit for cancer survivors as well. In repeated studies among patients with various types of cancer, high QOL was predictive of survival post-cancer even when

controlling for disease and treatment factors (Montazeri, 2009). Due to the invisibility of GBM and SGM patients in cancer care, it is unclear whether these same survival benefits are seen in this population. Theorizing that they do, however, indicates the importance of assessing and addressing disparities in QOL 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 appointments support, or other men with prostate cancer) and had a broader, more diverse social support network had higher quality of life. However the advantage of a broader social network of supporters 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 yet unclear, however, whether the impact of these social networks is felt across multiple domains of QOL for SGM survivors, or whether it is limited, as was shown for GBM. Also unclear is the primacy of sexual and physical QOL for other communities under the SGM umbrella, including lesbian and transgender patients.

The study by Capistrant et al. (2018) does have some limitations that impact interpretation of results. The authors dichotomized relationship status (as those currently in a relationship vs. those not in relationships). However, there is substantial evidence that outcomes differ for individuals in different relationship configurations (Goldsen et al., 2017; C. Kamen et al., 2015). For example, Aizer et al. (2013) showed that marriage confers a substantial survival benefit for (presumably) heterosexual patients; again, 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 Capistrant et al. sample of GBM with prostate cancer recruited online from <http://Malecare.org> is highly educated, with over 77% of respondents having a Bachelors degree or higher, and likely does 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, we must now begin to make changes 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 wellbeing 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 impact on treatment decisions by social support status, sexual outcomes risk, and financial toxicity. To aid in answering these questions, funding opportunities in the area of SGM and cancer exist, including the National Institutes of Health (NIH) Program Announcement: The Health of Sexual and Gender Minority (SGM) Populations.

Prostate cancer is a disease of aging, and GBM with prostate cancer are part of the ‘Silver Tsunami’ of older cancer survivors whose needs will outstrip the services and resources of our existing oncology healthcare structure (Bluthmann, Mariotto, & Rowland, 2016). The number of older survivors identifying as SGM more broadly will more than double by 2030

(Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emlet, 2015); they may face barriers to receiving formal healthcare due to fear of discrimination and may accumulate a greater financial strain due to a lifetime of disparities in earnings, employment, and access to legal and social programs compared to older non-SGM peers (Choi & Meyer, 2016). There is a need for policy addressing anti-discrimination legislation, expanding the definition of family to include chosen family, and recognizing SGM older adults as a greatest social need group by the Older Americans Act to prioritize funding for research and social services. Clinically, there is a need for culturally sensitive training for health and social service providers to support SGM older adults with cancer. Through research, policy and practice, nurses can play a pivotal role in bring the healthcare of hidden SGM patients and their caregivers to light.

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