

LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) SURVIVORSHIP

CHARLES KAMEN

OBJECTIVE: *To discuss lesbian, gay, bisexual, and transgender (LGBT)-specific survivorship issues including: integrating sexual and gender minority identities with cancer survivor identities; coordinating medical care and disclosing identities to health care providers; dealing with late effects of treatment; and addressing LGBT family and relationship issues.*

DATA SOURCES: *Published articles, quotes from an online survey of 311 LGBT survivors.*

CONCLUSION: *The transition from active cancer treatment to survivorship presents challenges, and LGBT cancer survivors may face additional challenges as they enter the survivorship phase.*

IMPLICATIONS FOR NURSING PRACTICE: *Oncology nurses can improve the quality of survivorship care delivered to LGBT survivors and their caregivers by addressing the disparities and gaps in health care.*

KEY WORDS: *lesbian, gay, bisexual, transgender, cancer, survivorship.*

Cancer survivorship has been variously defined as the time from cancer diagnosis through the balance of life, as the phase following cessation of cancer treatment, and as the point at which a patient is

in total remission following cancer treatment.¹ In this article, cancer survivorship is defined as encompassing the end of cancer treatment through the remainder of a patient's life. Transitioning from active treatment to survivorship presents unique challenges to all patients. Lesbian, gay, bisexual, and transgender (LGBT; also referred to as "sexual and gender minority") patients may experience additional challenges and opportunities based on their sexual and gender identities, their distinct medical needs, and their relationship and social support structures. Understanding these specific factors is critical to ensuring health equity for LGBT persons across the continuum of cancer.

Between 420,000 and 1,000,000 LGBT cancer survivors are estimated to live in the United States.^{2,3} LGBT survivors are comparable in number to other subgroups of cancer survivors that have been the

Charles Kamen, PhD, MPH: Assistant Professor, Department of Surgery, University of Rochester Medical Center, Rochester, NY.

This study was supported by National Cancer Institute grants K07 CA190529 and UG1 CA189961.

Address correspondence to Charles Kamen, PhD, MPH, Department of Surgery, University of Rochester Medical Center, 265 Crittenden Blvd, Box 420658, Rochester, NY 14642. e-mail: charles_kamen@urmc.rochester.edu

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0749-2081

<https://doi.org/10.1016/j.soncn.2017.12.002>

target of specific research and clinical attention,^{4,5} and yet they have remained invisible in psychosocial cancer research and in oncology clinics for decades.⁶ National databases and epidemiologic surveys do not routinely collect information on sexual orientation and gender identity, and assessments of cancer survivors' needs have remained relatively mute on the specific needs of LGBT survivors.⁷

The discussions in this article comprise LGBT-specific survivorship issues including: negotiating and integrating identity as a cancer survivor alongside sexual and gender minority identities; coordinating follow-up medical care with added anxiety about coming out to multiple health care providers; dealing with late effects of treatment while acknowledging a lack of information about the effect of cancer treatment on LGBT sexuality; and addressing family and relationship issues given the invisibility of LGBT persons' support systems in the cancer care continuum. Findings from a prior qualitative study will punctuate and underscore points in this discussion. In this study, conducted by Margolies and Stout,⁸ 311 self-identified LGBT cancer survivors (with a range of cancer types) from around the US completed an online survey. Data are included herein from qualitative responses to an open-ended survey question, which asked: "If you were to give a class to health care workers, focused on cancer care, what would you tell them about being LGBT and being diagnosed with cancer?"^{8,9}

IDENTITY ISSUES AND PSYCHOLOGICAL DISTRESS AFTER CANCER

Undergoing cancer diagnosis and treatment can be a frightening and stressful experience.¹⁰ Transitioning to the survivorship phase can also be stressful because patients are asked to leave the relatively responsive and predictable environment of the oncology clinic and seek additional medical services and supportive care on their own.¹¹ Following cancer diagnosis and treatment, cancer patients have to adapt to a "new normal." They must come to terms with the reality of their cancer experience and integrate a new identity as a cancer survivor alongside their other identities. They have to adjust to changes in their bodies, including scarring, fatigue, and cognitive changes. They have to cope with the stress of potential recurrence and seek routine follow-up care to ensure that they remain in remission.¹² Their loved ones and caregivers may

also experience considerable stress as they support the cancer survivor.¹³

LGBT cancer survivors may experience additional challenges when adjusting to the "new normal" of cancer survivorship and when integrating their identities as cancer survivors into their sense of self. LGBT survivors may have already grappled with identity issues throughout their lives because of minority stress.^{14,15} As defined earlier, minority stress comprises the chronic, underlying worry about discrimination and prejudice that an LGBT person may experience because of their stigmatized sexual or gender minority identities. Minority stress keeps some LGBT persons from fully accepting their own sexual and gender minority identities, and can lead to internalization of negative views about oneself that are derived from and reinforced by heterosexist (ie, privileging heterosexual individuals) and cisnormative (ie, assuming that all individuals' gender identities match the sex they were assigned at birth) societal structures.¹⁶ Given that identifying as a cancer survivor may carry with it a psychological cost and may induce additional stigma, layering a new identity as a cancer survivor on top of a sexual or gender minority identity may lead to a compounding sense of stigma.¹⁷ Research has yet to fully explore and unpack this possibility.

In addition to the stress of integrating a new identity post-cancer, cancer survivors may also experience continuing anxiety, depression, and psychological distress, even years after treatment.¹⁸ For LGBT cancer survivors, this distress may again be magnified by underlying, chronic minority stress. Studies have consistently shown that LGBT adults have 1.5 to 3.0 times higher rates of psychological distress than their heterosexual and cisgender counterparts.^{15,19,20} While the literature on psychological distress among LGBT cancer survivors is still in its infancy, the few studies conducted to date have suggested that disparities may exist. Boehmer and colleagues^{21,22} have demonstrated that lesbian and bisexual women with breast cancer experience poorer health-related quality of life than their heterosexual counterparts, and that unique factors predict their mental health. Similarly, Kamen and colleagues²³ found that gay men who had been diagnosed with cancer reported a higher number of days of poor mental health per month than their heterosexual counterparts. As a group, LGBT people are less likely to have adequate health insurance,²⁴ more likely to have experienced stressful discrimination based on their gender identity and/or sexual orientation,²⁵ and more likely to be alienated from

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