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Lesbian, Gay, Bisexual, and Transgender (LGBT) Survivorship

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Abstract

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 can improve the quality of survivorship care delivered to LGBT survivors and their caregivers by addressing the disparities and gaps in health care.

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 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

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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 their families of origin.²⁶ Layering these stressful life circumstances on top of the stress of coping with cancer could contribute to noted mental health disparities in LGBT survivors.

Describing the challenging interface of negotiating an LGBT identity and an identity as a cancer survivor, one woman in the online study described above stated, “My partner did not come to the hospital because the only good hospital around was a Catholic hospital and I didn’t want my treatment compromised by them finding out about my ‘sinful lifestyle.’ An anti-gay surgeon could easily ‘accidentally’ miss one of the many small lesions of the cancer or not take out an infected lymph node. An anti-gay nurse could take longer to give pain medicine. Being discovered as a lesbian in a Catholic hospital can be lethal when having cancer.”

A transgender man added, “My oncologist, who, still, after almost 2 years of seeing him every 3 months, continues to refuse to understand what being transgender means. I have an incredibly difficult and uncomfortable relationship with this doctor and no way to get out of it. The lack of respect for me is unbelievable.”

These difficulties with navigating LGBT identities in the context of cancer care could add considerable stress and distress to the already stressful experience of coping with cancer and moving from active care into survivorship. Given that existing studies have focused exclusively on lesbian/bisexual women and gay men, or were limited by the fact that national surveys do not specifically recruit LGBT cancer survivors and so have relatively small sample sizes,²² more research is needed to elucidate the relationship between identifying as a cancer survivor and the experience of stigma and distress among LGBT people.

Coordinating Medical Care as an LGBT Survivor

Cancer survivors state that one of the most difficult aspects of transitioning out of active treatment and into survivorship is coordinating medical appointments, screening, and supportive care services. Ensuring that other medical professionals (including nurses) are aware of the nature, duration, and type of cancer care received can also be challenging. Survivors report wondering: “Which doctors should I see?” “What should I tell my doctors

about my treatment?” “What screenings do I need now that I’ve already been diagnosed with cancer?”

Additionally, LGBT survivors may wonder, “Can I disclose my sexual or gender minority identity to my nurse or doctor?” “Will I be treated differently if I do?” “Will my chosen family be welcome?” “Will I be offered the information I need to know to take care of my relationship, my sexuality, my fertility, and my family?” LGBT survivors must grapple with the stress of asking these questions and worrying about disclosure of identity across multiple providers. As one survivor in the online study stated, “Although my doctor knew all about me, each encounter with new people—with blood draws, ultrasound, breast x-ray, etc.—had the basic anxiety of the procedure and layered on to that, the possibility of homophobia and having to watch out for myself.” Another survivor said, “Health care providers also need to be aware that homophobia and the closet are the biggest obstacles to LGBT health care. Many [LGBT patients] don’t go because of homophobia they’ve experienced from doctors, or they don’t get the proper care because they can’t disclose that they’re LGBT (which might figure into a diagnosis). A health care provider should be a safe space for everyone, because health care is so important to individual and community health.”

In addition, the absence of data regarding the particular health needs of LGBT cancer survivors have limited the number of medical recommendations and guidelines specific to this population. This is especially true for trans* patients, who may wonder about continuation of hormone treatments during and after cancer treatments.²⁷ Screening guidelines for cancer survivors are similarly mute about trans* survivors taking hormones. How often should a transgender man or genderqueer/non-binary survivor present for breast or cervical screenings (if applicable)? How often should a transgender woman or genderqueer/non-binary survivor (ie, with a gender identity that is not exclusively feminine or masculine) present for prostate screenings (if applicable)? Further research is needed to establish empirically based recommendations.

Certain subgroups of LGBT survivors, in particular gay/bisexual men and transgender women, are at increased risk for experiencing comorbid infection with HIV and cancer.²⁸ Negotiating HIV and cancer survivorship simultaneously carries with it a host of complex pragmatic and psychological factors.^{29,30} As one survivor in the online study stated, “I have told everyone about my cancer, which was diagnosed last year, but I still haven’t told anyone other than my husband about my HIV diagnosis from 7 years ago. I am almost grateful for the cancer to allow me to be at least a little more open and honest about my health without actually disclosing my HIV status.” Another survivor reported, “I now do presentations in regards to Cancer and HIV, since I have been living with HIV for over 27 years.” LGBT survivors diagnosed with both cancer and HIV may have unique risks for complications, side effects, and late effects as a result of treatment interactions, and may need to integrate care recommendations from infectious disease specialists, oncologists, and primary care physicians.

Dealing With Late Effects of Treatment

The natural progression of cancer as a disease can produce diverse symptoms in cancer patients. In addition, cancer treatment can produce additional toxicities and symptoms, ranging from fatigue to chemotherapy-related cognitive impairment to cardiotoxicity. Some of these symptoms may not become evident until months after treatment and may linger for years into the survivorship phase. All cancer survivors must worry about and manage these symptoms and the concomitant changes to their bodies.

LGBT survivors may have to deal with additional unique late effects of treatment related to their sexuality, and these late effects may not be fully addressed by medical providers accustomed to treating heterosexual and cisgender survivors.³¹ Providers who do make an attempt to address their patients' sexuality-related needs may rely on printed educational materials instead of frank discussion about sex and sexuality. Many of these booklets assume that survivors are in a heterosexual married relationship, though this trend is beginning to change and the word "partner" is being used more often in both printed and online documents.

LGBT sexuality is not identical to heterosexual sexuality, however, and a simple change in partner nouns or pronouns may fail to capture this complexity. Many LGBT people engage in sexual practices that may not be addressed in printed materials and may be beyond the scope of knowledge or comfort of medical and social service providers. For example, prostate cancer treatment often compromises erectile functioning.³² Health care providers may feel competent and comfortable in discussing men's options for vaginal penetration post treatment, but a gay survivor may not be able to find information about anal penetration, which requires a firmer erection, even if he is willing to be out to his provider and ask direct questions.³³ Similarly, a gay survivor who engages in receptive anal intercourse needs specific information about his options to remain sexually active following treatment. Lesbian women may have to discuss and reflect on intimacy with their partners following breast cancer treatment and mastectomy.

As one survivor told us, "I think we might be able to discuss more openly how sex and sensuality can be an important part of coping/healing/recovery processes. I thought this aspect was underplayed and even stigmatized in most environments, but to me it was one of the reasons I fought to survive." Another, however, said, "Luckily my radiologist could talk about how the treatment might affect my sex life and used terms and concepts that indicated an understanding of gay men's sexual behavior (for example, he asked who was the top and who was the bottom etc.)." Some LGBT survivors displayed resilience in the face of changing sexual expression: "As a lesbian I have a good body image. The decision to have a mastectomy was easy...And my partner was supportive. We didn't need my left breast to make love."

The need here is two-fold. On the one hand, health care providers must be willing and able to discuss sexuality following cancer treatment without falling back on heterosexual assumptions. This will require first, that providers feel comfortable discussing survivors' sex lives, and second, that they know survivors' sexual and gender identities. In addition, health

care providers must possess information about LGBT sexuality that they can impart to survivors. This will require more research, better guidelines, and diverse materials that can be offered to LGBT survivors concerned about the sexual side effects of treatment.

Many younger cancer survivors, including LGBT survivors, are concerned about the impact of treatment on their fertility. Unfortunately, reliable information about this topic is inconsistently conveyed to survivors of any sexuality or gender identity.³⁴ The information that is available, whether through printed materials, oncology social workers, nurses, or doctors, often assumes that childbearing will only be a concern for legally married, heterosexual patients. When they are out to their providers, it is therefore often assumed that LGBT survivors will not want fertility information, even though many LGBT people choose to use alternative forms of insemination and surrogacy.³⁵ As one survivor in the online study stated, "Please offer us fertility options."

Family and Relationship Issues

Cancer survivorship is rarely a solitary experience. Many cancer survivors have caregivers, including spouses, family members, and friends, who have supported them through their cancer experience. Once treatments have ended, cancer survivors must educate family members and loved ones about their new physical capabilities, and about any toxicities and side effects of treatment they are experiencing. They also need to continue to receive support from others as they progress toward recovery.

While many cancer survivors rely on their family for support, it is not uncommon for LGBT people to be alienated from their family of origin because of their gender identity and/or sexual orientation.³⁶ Therefore, social support for LGBT survivors may look different than support for heterosexual and cisgender survivors, and may be invisible to health care providers who do not understand or recognize the importance of non-family members and non-spouses. These supportive others may be inadvertently excluded from providing care or assisting with medical decision making. Rather than (or in addition to) family members, LGBT people may rely on their partner, their ex-lovers, and their friends to provide support.³⁷ To underscore this point, in the internet-based survey, 77% of the LGBT respondents reported that friends were a part of their personal and emotional support system during cancer diagnosis and treatment. This was higher than the percentage reporting that their partner (62%), their parents (40%), or their siblings (40%) were part of their support system. By contrast, heterosexual and cisgender cancer patients are most likely to name a spouse as their primary source of personal and emotional support.^{38,39}

Acknowledgement and integration of diverse caregivers is a need, not only of the LGBT cancer survivor, but of the caregiver. In general, caregivers of cancer survivors tend to experience distress and burden,^{39,40} and this stress may be exacerbated by lack of acknowledgement by the cancer care team. Including diverse caregivers in the sharing of clinical data and the making of medical decisions can improve outcomes for LGBT survivors and caregivers alike. While no studies have specifically examined the needs of LGBT survivors' caregivers, research on the LGBT community in macrocosm has shown that support is just as important to LGBT adults as it is to heterosexual and cisgender adults,

if not more so.⁴¹ Social policies that overtly refuse to acknowledge LGBT support systems and relationships have a negative impact on the health and wellbeing of LGBT persons.⁴² These same trends are replicated, and perhaps magnified, in health care clinics.

As one survivor wrote, “My lover at the time and my ex bonded together to support me for over 2 years. My friends and community and doctors wrapped themselves around me.” A gay man concurred: “My partner IS MY FAMILY and when they treat him as such my outcomes are much better. He is my advocate and can remember everything I can’t. Good outcomes depend on his involvement as does my emotional wellbeing.” By contrast, a lesbian survivor added, “She (my partner) was generally welcomed but treated as a ‘friend’ not a ‘spouse’ and caretaker. She was never really offered emotional support by the treatment team as I noted other (straight) patient’s partners and caregivers were. She was never offered access to caregiver’s supports or resources.”

A transgender survivor told us, “ My support system, many of whom are trans and gender variant people, were made to feel very uncomfortable by my doctors and medical staff due to disregard for pronoun use, sideways glances, and overall awkward responses. My friends comprised my entire support system and were critical to my care. The reluctance to respectfully interact and, in some cases, communicate clearly with my friends was extraordinarily difficult for me and lead to much added stress. I already felt so alone without my family.”

Acceptance, welcoming, and respect for these diverse caregivers is a pervasive need of LGBT survivors. In addition, few services are tailored to the needs of diverse caregivers. Same-sex romantic partners may feel excluded from support groups and other services that include primarily spouses of cancer survivors. Friends or ex-partners, similarly, may feel they do not belong in such settings. Couples services that target married heterosexual couples may not be able to address the needs of same-sex couples. There is a need for additional services for these diverse caregivers.

Recommendations and Future Directions

Based on the issues common to all cancer survivors and the experiences shared by LGBT survivors in particular, these four recommendations may serve to improve the quality of survivorship care delivered to LGBT cancer survivors:

1. Ensure Cultural Competence in all Staff Across Medical Practices

Nurses, physicians, clerical staff, and health care management working across health care clinics should take steps to become educated about the stigma-related stress that LGBT survivors may carry into treatment. As highlighted earlier, the stress of transitioning from treatment to survivorship may be magnified for LGBT survivors, who must navigate disclosing their identities to a potentially new set of providers. Health care facilities may investigate strategies to reduce such stress, both by inviting LGBT survivors to come out to their providers and by welcoming their caregivers into medical decision making. In the internet-based survey, 58% of participants who had come out did so to correct a heterosexual or gendered assumption made by their provider. This underscores the importance of having a

culturally competent and welcoming environment where LGBT survivors are invited to disclose in safety. In addition, providers should be educated in how to speak about sex and sexuality to LGBT survivors and how to ask about their social support networks and needs.

In the words of a participant in the internet-based study, “There are still doctors and others of different cultural and religious backgrounds that have negative feelings towards LGBT individuals. As a result, it is very difficult to openly discuss one’s sexual orientation for fear of rejection and non-interest in one’s health matters.” By contrast, another participant stated, “We live in New York City—in a very gay neighborhood and my treatment was at a very ‘gay hospital.’ Being an out lesbian in a serious monogamous relationship was not particularly an issue, nor was the presence of my partner in the hospital or during my treatment.” The welcoming stance, or lack thereof, of the cancer care facility can thus have a pervasive effect on LGBT survivors’ experience of care.

2. Collect Referral Lists for LGBT-Welcoming Services, Including Local Support Groups

Understanding that many culturally competent services are offered outside of the oncology clinic, it is important to develop a referral list of providers and services that are LGBT welcoming.

As one lesbian breast cancer survivor put it, “I ended up going to a support group where I was the only queer woman. They were great people and my being out wasn’t a problem, but I missed having that support. The local LGBT health org did not have an active support group at the time for queer women going through cancer treatment. Very unfortunate. Ironically, my partner had a support group to go to at this place, but I didn’t.” From another: “The support group I was offered was the one provided at the hospital. I was the only queer person in the room and while the leaders were very well-meaning, there were moments of alienation (I spoke up but still) especially when the topic of sex and cancer came up.”

LGBT groups focused on particular cancer types would be ideal, as highlighted by this participant: “Having a gay male support group was the best thing that happened to me. I feel very lucky to be able to discuss both feelings and sensations without any inhibition at all in the company of other gay men who also had prostate cancer.”

3. Broadcast LGBT Welcome Through Collaborations With Community-Based Organizations and Media

After setting up a foundation of cultural competence, health care institutions and offices should broadcast their LGBT-welcoming policies and training to potential and current patients. This is best accomplished both within and outside of the facility. For example, LGBT patients and caregivers often look for posted nondiscrimination signs that include mention of sexual orientation and gender identity. They notice the art on the walls, the printed materials in the waiting room, and they may look to see if there are images that reflect themselves. Is there a rainbow sticker or a Safe Space symbol? Is there a gender-neutral bathroom? Does the intake form offer options that reflect LGBT gender identities and relationship statuses?

Active welcoming of LGBT survivors may involve posting symbols to indicate openly that the clinic and its providers support the LGBT community. It may also involve statements by providers and staff to indicate inclusiveness of LGBT patient perspectives. These statements may include use of non-heterosexist, gender-inclusive language when dealing with patients, positive response to LGBT survivors' disclosures, and welcoming of LGBT survivors' caregivers. As one participant said, "It would have gone much better if there was some indicated awareness that as a patient I had a sexual orientation that they cared to know about and that I could be assured of being accepted and treated with the same quality of care as anyone."

Visible advertisement of a clinic's welcoming stance toward LGBT survivors must go beyond the treatment facility itself. Collaboration and networking with LGBT community organizations can help to spread the word that a particular clinic or set of providers is non-discriminatory and LGBT affirming. Such networking may include advertisements in LGBT newspapers, presence at LGBT health fairs, or simply communicating with local LGBT community leaders. Advertisement of a welcoming environment can be underscored by introduction of a clinic non-discrimination policy that includes LGBT identity. Making this policy explicit to providers and staff will reinforce the importance of treating all patients with respect and dignity, regardless of sexual orientation and gender identity.^{27,43}

5. Review and Revise Social Support Programs

To ensure LGBT welcome and usefulness, social support programs must be reviewed, revised, and tailored to meet LGBT survivors' unique needs. Shallow and deep tailoring approaches could ensure that these programs reach and resonate with the LGBT population.⁴⁴ Shallow tailoring could simply involve including pictures of same-sex couples and LGBT individuals, or testimonials from LGBT survivors, in materials aimed at providing general information about cancer. The LIVESTRONG brochure on "Coming Out with Cancer," for example, contained information similar to that used in the LIVESTRONG brochure for heterosexual survivors; however, this information was interspersed with images and testimonials from LGBT survivors.³ Once tailored, the information may need to use specialized outreach to access LGBT survivors.

Some interventions may need to undergo deep tailoring, however, before they will be applicable to LGBT survivors. For example, therapies aimed at addressing sexuality concerns for breast and prostate cancer survivors may need to account for the experiences of LGBT patients in this domain.^{33,45,46} Supportive care for anal cancer among gay and bisexual men may need to address sexual side effects of this type of cancer, which may not be relevant for heterosexual survivors.⁴⁷ New interventions may be required to address specific disparities noted in LGBT populations, such as disparities in rates of psychological distress and substance use.

In addition to these clinical and policy recommendations, additional research is needed to focus on the distinct needs of LGBT cancer survivors. Such research could begin with an examination of the symptoms LGBT survivors find most troubling, services they lack, behavior change needs, and the needs of their support systems and caregivers. Once these needs have been delineated and described, research must move into development, testing,

and dissemination of interventions. Merely highlighting the issues is not sufficient; the field must also begin to address disparities and gaps in service for LGBT survivors and their caregivers, thereby improving the health and well-being of this underserved and underrepresented population.

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