

Gay and Lesbian Patients With Cancer

Anne Katz, RN, PhD

The disease trajectory in cancer involves a complex system of treatment choices, multiple treatments over an extended period of time, and significant physical and emotional side effects that impact people from all demographics. However, little published research has explored the cancer care experience of gay and lesbian patients, an invisible minority who have been discriminated against by society and within the healthcare system. Many gay and lesbian individuals have had negative experiences in the healthcare system (Klitzman & Greenberg, 2002); as a result, this study sought to identify whether those patients have similar issues when diagnosed with cancer.

Homophobia and discriminatory practices among healthcare providers have been reported in the literature. Gay and lesbian patients do not always disclose their sexuality to healthcare providers (Rankow, 1995). Studies suggest that some lesbian patients have difficulty disclosing their sexuality to physicians (Matthews, 1998), but most do not experience discrimination (Sinding, Barnoff, & Grassau, 2004).

In a study of lesbian and bisexual women with breast cancer, 72% disclosed their sexual orientation to their cancer care providers; those who did not noted that the care provider did not ask (Boehmer & Case, 2004). The passive nondisclosure was attributed to fear of homophobia, being single, and a belief that sexual orientation is private. Reasons given by women who actively disclosed included perceived safety of the environment and preparatory work by patients who sought care from providers believed to be positive and understanding. All participants in the study reported that they needed to remain vigilant in their encounters with healthcare providers and that their interactions were fraught with apprehension.

In a comparative study of heterosexual and lesbian women with breast cancer, lesbians reported higher stress associated with diagnosis and treatment, lower satisfaction with care provided by physicians, and a trend toward lower satisfaction with emotional support from healthcare providers (Matthews, Peterman, Delaney, Menard, & Brandenburg, 2002). Fobair et al. (2001) found that, in addition to differences in received medical care and social support, lesbians experienced

Purpose/Objectives: To describe the cancer experience of gay men and lesbian women.

Research Approach: Descriptive, qualitative analysis.

Setting: Ambulatory cancer center in a midsized Canadian city.

Participants: 3 gay men and 4 lesbian women with cancer.

Methodologic Approach: In-depth, face-to-face interviews were conducted with a semistructured interview guide. Transcribed interviews were analyzed, and themes were identified within and among individuals.

Findings: Coded transcripts of the interview data yielded four themes: Disclosure related to individuals' experiences in revealing their sexual orientation to cancer care providers, Response to Partner described the role of partners in the care continuum and healthcare providers' responses to the presence of same-sex partners, Support From Others addressed the lack of support groups for gay and lesbian clients, and Body Image concerned the alterations to physical appearance resulting from cancer and its treatments and the unique role that image plays in gay and lesbian communities.

Conclusions: Overt homophobia or discrimination within the cancer care system was not experienced by this study's participants. Participants valued the central role of their partners in coping with cancer. Some gaps in the cancer care system related to support groups were identified.

Interpretation: Although the participants did not experience overt discrimination in the cancer care system, nurses should continue to ensure that sensitive care is provided to the gay and lesbian population.

more distress about altered body image than heterosexual women.

Methods

A qualitative approach was used in the present study to elicit the subjective experiences of the participants. Interpretive phenomenology was the guiding methodology because the aim of the study was to understand the cancer experience from the perspective of the participants. Phenomenology, which builds on the work of Heidegger (1962), has been used widely in qualitative research. Bracketing (holding the researcher's preconceived beliefs and opinions about the topic in

abeyance) is central to conducting phenomenologic research.

Recruitment

A convenience sample of gay men and lesbian women with cancer was recruited from an ambulatory cancer center in a midsized Canadian city. Inclusion criteria were speaking English and having a history of cancer or cancer treatment. Because of privacy laws in Canada, the investigator could not verify cancer diagnoses with staff or from the patients' charts, so diagnoses were accepted as stated by the participants. Posters advertising the study with tear-off tags giving the investigator's phone number were displayed in examination rooms in the cancer center. An advertisement also was published in the print and online versions of the local gay and lesbian monthly newspaper. Recruitment continued and interviews were conducted until data saturation was reached.

Procedure

Approval was obtained from the University of Manitoba ethics review board and the Research Resource Impact Committee of CancerCare Manitoba, where the study was conducted. Interested participants contacted the investigator by telephone, and the details of the study were explained. An appointment for the interview was made with those who agreed to participate. Four of the seven interviews occurred in the investigator's office and the other three in the participants' homes. After participants signed written consent forms, semistructured interviews were conducted by the investigator and recorded with a digital voice recorder. Interviews lasted 45–126 minutes and continued until no new information was presented and data saturation was achieved. The investigator transcribed recorded interviews verbatim into longhand, removed identifying information, and typed the transcripts.

Interview Guidelines

Each interview opened with the question, "Tell me about your cancer experience." Probes were used to increase the detail of the data and included questions about disclosure to healthcare providers, experiences of partners, and sources of support. Most participants did not need probes and volunteered rich descriptions of the cancer experience in ongoing narratives.

Data Analysis

The transcribed interviews were read repeatedly by the investigator. The present study used a method of data analysis described by Cohen, Kahn, and Steeves (2000) in which words and phrases (codes) that might delineate themes were identified and noted in the margins of the transcripts. Similar codes were grouped together into four themes.

Member checking was used to validate the data. Three participants reviewed the findings and stated that the data were reflective of their experiences. In addition, psychosocial clinicians who provide care and support to patients with cancer at CancerCare Manitoba also confirmed the findings.

Findings

Three gay men and four lesbian women aged 31–69 years participated (see Table 1). Six had at least graduated college, five had an annual household income higher than \$50,000, and all were Caucasian. Two men and one woman were single; all others were in partnered relationships. One woman had two separate cancer diagnoses, and another had a recurrence of her primary cancer six years after initial diagnosis and treatment. Coded transcripts of the interview data yielded four themes: Disclosure, Response to Partner, Support From Others, and Body Image.

Disclosure

All participants had informed their cancer care providers that they were gay or lesbian. Some mentioned their same-gender partner by name at an early appointment; others stated that they were gay or lesbian. All believed that their healthcare providers should know because sexuality was an integral part of their lives and who they are, not because they expected different treatment. A woman stated, "[It was important] to not be dancing around with who I am as a person and who my support people are. I think also that in a way we can do something to normalize gays and lesbians in the eyes of the larger community." Some participants received a positive response when they disclosed; for others, the response was neutral or the disclosure was even ignored.

Table 1. Demographic Characteristics

Participant	Age (Years)	Gender	Type of Cancer	Years Since Diagnosis
A	47	Male	Melanoma	1
B	31	Male	Osteosarcoma	6
C	39	Male	Colon	5
D	55	Female	Endometrial	1
E	69	Female	Breast Lymphoma	10 5
F	46	Female	Cervical Recurrence	10 4
G	51	Female	Tongue	1

I was out with my surgeon. After the first couple of sentences, I said, "My partner [X] will be here," and stuff like that. [The physician] didn't really care. . . . He is very focused on what he has to do.

A woman who was diagnosed with her first cancer years earlier experienced difficulty when a receptionist was entering her demographic data in a computer.

I think the reluctance to accept my partner was because it didn't fit their computer screens. It's better now because of better staff training and now it's legal for gays and lesbians to be married (in Canada), so it's hard not to have a place on the form for those kinds of relationships.

Response to Partner

The presence of a partner was central for participants in partnered relationships at the time of diagnosis or treatment. One woman was afraid that her partner would not be recognized and included in the treatment process.

At the time, my biggest concern was that, under the law, my partner had no standing, so we went through this process. . . . How would she be treated? Would her wishes be respected? Would my wishes regarding her presence be respected? Fortunately, all throughout the process I found that people in the system were extremely respectful of our relationship.

The role of partners in supporting patients with cancer also was acknowledged. A young gay participant described the importance of being accepted by one's partner.

I needed someone who I could break down in front of and he was the person there. . . . You need to feel like your life hasn't changed that much. . . . You're still an attractive being and you're still desirable, especially by the person you love.

In addition, a woman recognized that affection from a partner was of paramount importance. "I have a partner who loves me for who I am, who is absolutely unwavering in that." Another woman said, "I can't imagine how difficult it would have been to have done this without a partner. It made a huge difference to me."

Support From Others

The participants identified the lack of support groups for gay and lesbian patients with cancer as a weakness in the healthcare system. A woman who had not disclosed her sexuality to her support group felt that her support experience was limited. She said, "I am not 'out' in that group and so only part of me is really able to benefit from that experience." She felt that in hiding her identity, she had "chosen to not fully be there." Another woman acknowledged the difficulty of disclosing sexuality to a support group. She described

attending with her partner, who introduced herself as a support person at the first meeting and as the partner at the second. She said, "It wouldn't necessarily have been appropriate if I had gone by myself to say, 'Hi, I have cancer and I'm a lesbian.'" However, one woman believed that the lack of targeted support groups does not affect mutual support for gay and lesbian patients: "I don't think I'd get any different treatment, even at the support group, if I were to say I'm a lesbian. They'd say, 'What's different in what you want to talk about?'"

A lesbian participant described difficulty when she asked an ostomy volunteer (another woman who had had similar surgery) about sexuality with a stoma. She criticized the volunteer's inappropriate response.

I'm not saying they have to be queer [sic] people to talk to queer people, but at least they need to know that it's possible that the person you're going to go and see may be a queer person and maybe you have to be comfortable with that.

Body Image

All participants commented on the alterations to body image caused by cancer treatment. Of interest is that the men believed that lesbian women are less concerned about body image than gay men; some lesbian participants made the same assumption. However, a woman voiced concerns about physical appearance; she said that without her partner, "I'd have a tough time getting my head around dating again. . . . I have big scars. I think that if I were not in a stable relationship, this would be a major issue for me."

Men in the present study recognized that physical appearance is important in gay culture, so being partnered and having one's partner show acceptance of treatment- or disease-related physical changes was of particular comfort. A man who was partnered when he was first diagnosed broke up with his partner during treatment. When he was single again, he realized,

It has a lot to do with body image. It's a very sexually charged community and I think that dealing with your new shape, your new form, wondering how people are going to perceive that . . . I found that over time, and maybe because I was single again, the body image thing grew—where you become more conscious of how you look and how you present to others.

A man described his reaction after surgery.

I lost 25 pounds within a week because of surgery, and I was really drained—you could tell the weight loss was so fast, and when I got out of the hospital and friends dropped by, I wondered if it was going to be perceived within the gay community as having AIDS.

Another gay participant corroborated: “In the gay community, when you look really sick, what do people think? They don’t think cancer.”

Discussion

The four themes identified in the present study reflect the cancer experiences of the seven participants. For gay and lesbian patients with cancer, the usual challenges of diagnosis and treatment are further complicated by the need to disclose sexual orientation, which may be difficult based on previous negative experiences. However, the participants willingly and openly disclosed to healthcare providers and recognized the importance of their partners. A deficit identified in the healthcare system was the lack of same-sex support groups. In addition, a response to body changes common to all people was experienced by gay and lesbian patients.

The mostly positive experiences with the cancer care system described by the seven men and women may represent changing attitudes in society. The study was conducted in a midsized Canadian city in a province where same-sex marriage has been legalized since 2004, which may have influenced the widespread acceptance of partners by healthcare providers and undoubtedly has improved societal attitudes toward same-sex relationships. As a result, the findings may not generalize to other jurisdictions in Canada or the United States that do not recognize same-sex unions or are socially conservative.

Previous studies have suggested that disclosure to healthcare providers was difficult and that patients had to remain vigilant to protect themselves from potentially upsetting interactions (Boehmer & Case, 2004). However, the overwhelming perception of the present study’s participants was that their healthcare teams were supportive and encounters were not stressful.

Although providers’ reactions were described as gay-neutral and accepting rather than gay-positive, all participants in the present study were satisfied with the care provided. Matthews et al. (2002) found that lesbian women tend to introduce their partners to healthcare providers to ensure equality of care but hide their sexuality from other members of support groups, similar to the women in the present study.

As with heterosexual patients, partners are central for support in the cancer experiences of gay and lesbian patients. The lack of targeted support groups for gay and lesbian patients distressed most of the participants, but the study was conducted in a small city; larger centers should have the population base to support same-sex support groups specific to certain cancers. In the present study, gay men expressed more concern about body image than lesbian women; however, all patients worried about scars in the context of dating. The generally positive results of the present study reflect a healthcare system

that accepts same-sex couples and is nondiscriminating in the care of gay and lesbian patients with cancer.

Strengths and Limitations

The similar experiences of men and women and the agreement among participants with a wide age range and seven different types of cancer were strengths of the present study. The small sample size may have been a limitation; however, data saturation was reached quickly, so the study was stopped after seven interviews. Psychosocial clinicians who work with gay and lesbian patients supported the identified themes and concurred that the findings represent the experiences of their clients.

As with any convenience sample, bias may exist in the participants who volunteered to be interviewed. All participants had positive experiences, meaning that gay and lesbian patients with bad experiences may have avoided participating. However, people who have had negative experiences generally seek opportunities to talk about them, so the absence of dissenting participants in the present study is remarkable.

Implications for Nurses

The present study’s findings show that homophobia does not affect the current cancer care experiences of gay and lesbian patients, and the support of same-sex partners appears to be accepted by healthcare providers. However, providers should be careful to use gender-neutral language until patients indicate the gender of their partner. Asking a patient whether his or her partner will be present rather than husband or wife prevents gay and lesbian patients from feeling excluded. Neutral language also should be included in the registration forms that patients must complete in healthcare facilities. The choices *single*, *married*, *separated*, *divorced*, or *widowed* do not reflect the lifestyles of most gay men and lesbian women as well as unmarried heterosexual couples.

Nurses should consider the needs of gay and lesbian patients and find ways to support them. Although support groups for gay men or lesbian women with specific cancers may be difficult to organize and maintain logistically, general support groups that are not disease-specific may meet the needs of gay men and lesbian women. In addition, nurses can establish informal support networks by asking patients to contact each other outside of the group setting.

Providing sensitive care to gay men and lesbian women includes avoiding assumptions. Every cultural group has unique norms, values, beliefs, and ways of doing and talking about things, and the gay and lesbian population can be considered separate from dominant heterosexual culture. Heterosexual healthcare providers may make erroneous and hurtful assumptions about gay or lesbian

patients, thus creating barriers to care. Like heterosexual women, a lesbian women with breast cancer probably would rather be asked what role her breasts play in her sexual life than for the nurse to assume that the loss of a breast would be catastrophic for the patient.

To date, most practicing nurses have not had formal education related to gay and lesbian patients. The author has observed that many nurses have been raised in conservative homes and practice in small communities in which gay or lesbian individuals and families may not be apparent. Although some nurses are accepting, receptionists, students, residents, and other healthcare professionals at facilities who have equal opportunities to interact with gay and lesbian patients may cause emotional harm with their words and actions.

Most educational material given to patients and posters displayed in hospitals and clinics contain few, if any, images of same-sex couples. Such minor details are important to gay and lesbian patients and may influence their comfort in disclosing sexual orientation. Gay- and lesbian-friendly resources are available in most communi-

ties; nurses should familiarize themselves with the names and contact information of gay-friendly or gay-identified counselors and other healthcare providers.

The present study's positive findings related to acceptance of disclosure by healthcare providers suggest that society's attitudes have improved and that gay or lesbian individuals should disclose their sexual orientation to healthcare providers when entering care. Disclosure may result in better care by allowing healthcare providers to know the whole patient. A diagnosis of cancer is a life-altering event, and the treatment experience often is stressful. Nurses should help all patients negotiate the cancer experience in a holistic and supportive manner; therefore, being inclusive and accepting gay and lesbian patients are professional responsibilities.

Anne Katz, RN, PhD, is a clinical nurse specialist at CancerCare Manitoba in Winnipeg, Canada. No financial relationships to disclose. Katz can be reached at anne.katz@cancercare.mb.ca, with copy to editor at ONFEditor@ons.org. (Submitted December 2007. Accepted for publication June 19, 2008.)

Digital Object Identifier: 10.1188/09.ONF.203-207

References

- Boehmer, U., & Case, P. (2004). Physicians don't ask, sometimes patients tell. *Cancer*, 101(8), 1882-1889.
- Cohen, M., Kahn, D., & Steeves, R. (2000). *Hermeneutic phenomenological research*. Thousand Oaks, CA: Sage.
- Fobair, P., O'Hanlan, K., Koopman, C., Classen, C., Dimiceli, S., Drooker, N., et al. (2001). Comparison of lesbian and heterosexual women's response to newly diagnosed breast cancer. *Psycho-Oncology*, 10(1), 40-51.
- Heidegger, M. (1962). *Being and time*. New York: Harper Collins.
- Klitzman, R., & Greenberg, J. (2002). Patterns of communication between gay and lesbian patients and their healthcare providers. *Journal of Homosexuality*, 42(4), 65-75.
- Matthews, A.K. (1998). Lesbians and cancer support: Clinical issues for cancer patients. *Health Care for Women International*, 19(3), 193-203.
- Matthews, A.K., Peterman, A.H., Delaney, P., Menard, L., & Brandenburg, D. (2002). A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer. *Oncology Nursing Forum*, 29(10), 1455-1462.
- Rankow, E.J. (1995). Breast and cervical cancer among lesbians. *Women's Health Issues*, 5(3), 123-129.
- Sinding, C., Barnoff, L., & Grassau, P. (2004). Homophobia and heterosexism in cancer care: The experiences of lesbians. *Canadian Journal of Nursing Research*, 36(4), 170-188.