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ORIGINAL ARTICLE

"Treat us with dignity": a qualitative study of the experiences and recommendations of lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients with cancer

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Abstract

Purpose Despite indications that lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients have unique needs when seeking healthcare, the experiences of LGBTQ patients in the context of cancer care have not been fully explored. This qualitative study investigated recommendations offered by LGBTQ patients with cancer for improving cancer care.

Methods Two hundred seventy-three LGBTQ people across the USA who had been diagnosed with cancer completed an online survey that included open-ended questions. Using responses to these questions, two researchers independently conducted open coding. A code book was generated collaboratively and the data were coded independently. Codes were clustered and refined and the data were independently re-coded.

Results Five themes emerged. LGBTQ patients with cancer: (1) are affected by providers' LGBTQ-specific knowledge and skills, assumptions, and mistreatment; (2) negotiate disclosure of identities based on safety of clinical encounters; (3) have differing experiences based on multiple intersecting identities; (4) receive more effective care when members of their support networks are included; and (5) are self-advocates and undergo transformative experiences in the face of morbidity and marginalization.

Conclusions LGBTQ cancer survivors report challenges accessing competent cancer treatment. To address this, cancer care providers should provide safe clinical encounters, inquire about and respond professionally to patients' identities and identifiers, include chosen support people, provide care relevant to patients' gender identities, and address treatments' effects on sexuality. Training providers about diverse LGBTQ communities and acknowledging the strengths of LGBTQ patients with cancer may improve provider/patient relationships. Provider training could be created based on these principles.

Keywords Cancer · Sexual orientation · Gender identity · Health disparities · Sexual and gender minorities

Introduction

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals have unique experiences and needs in the context of cancer care relative to their heterosexual and cisgender (i.e., those whose sex assigned at birth matches their gender identity) counterparts [1, 2]. For example, an LGBTQ patient with cancer must decide whether, when and how to disclose their sexual orientation and/or gender identity to their cancer care providers [3] and may experience poor health outcomes if they do not disclose [4] or mistreatment if they do [5]. LGBTQ people with cancer may be less likely to rely on support from biological family due to historical rejection or non-acceptance [6] and may instead include friends and current and former partners in their support network. [7] LGBTQ patients and their caregivers may have difficulty accessing support services

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that primarily serve heterosexual and cisgender patients. For example, female partners of women with breast cancer may feel discomfort attending a caregiver support group attended primarily by heterosexual male partners [8].

Many studies of LGBTQ patients with cancer have used nationwide, quantitative datasets and have found disparities in cancer risk factors and cancer outcomes between certain LGBTQ subgroups and their heterosexual and cisgender counterparts [2, 9]. However, quantitative surveys, by virtue of their structured questions, cannot elicit nuanced, idiographic suggestions regarding what LGBTQ patients feel their doctors should learn about sexual orientation and gender identity in healthcare. A few qualitative studies focusing on sexual minority women have used semi-structured interviews to assess factors impacting disclosure and the experiences of the support people of LGBTQ people with cancer [8, 10]. However, there is little known about the breadth of experiences of LGBTQ patients with cancer and the specific recommendations they have for providers. Such data are necessary in order to improve cancer care delivery based on the perspectives and priorities of the LGBTQ community. [11] We elicited qualitative data from a nationwide sample of LGBTQ patients with cancer participating in an online survey, with the dual aims of collecting descriptive information about their experiences and assessing their recommendations for cancer care providers.

Methods

Research design

This study follows the STROBE guidelines for reporting results of observational studies [12]. Data for this qualitative analysis were drawn from two open-ended qualitative items included in an online survey designed to assess cancer care experiences of LGBTQ patients. The qualitative items were: “If you were to give a class to healthcare workers, focused on cancer care, what would you tell them about being LGBTQ and being diagnosed with cancer?” and “If there is anything else you would like to add about your experience of being diagnosed with cancer, please write it here.” Quantitative questions on this survey assessed sociocultural aspects of coping with cancer; findings from these questions have been described previously. [6]

Recruitment and procedures

Participants were recruited through LGBTQ-specific websites, blogs, newsletters, and e-mail blasts. To be included in the survey, participants had to (1) self-identify as lesbian, gay, bisexual, and/or transgender, (2) report a diagnosis of cancer (any type or stage; no limit on time since diagnosis), (3) be over age 18, and (4) be able to read and write in English. There were no additional exclusion criteria. The online survey was posted through Zoomerang from January 2012, to April 2012. As the study was anonymous, no incentives were provided. This study was approved by the Institutional Review Boards of California State University, San Bernardino and the University of Rochester.

Participants and measures

A total of 311 participants began the survey and 273 responded to the qualitative items. The final sample included these 273 adult LGBTQ people with a history or current diagnosis of cancer. As this was a secondary, qualitative analysis, no a prior sample size calculation was performed.

The survey assessed participant demographic characteristics, including year of most recent cancer diagnosis, primary site of most recent cancer, gender identity, sexual orientation, race/ethnicity, and relationship status at time of diagnosis. Gender identity response categories provided on the survey were “transgender FTM (female-to-male)” and “transgender MTF (male-to-female);” we report those items as “transgender man” and “transgender woman,” respectively. Other response options were “female” and “male,” which we report as “cisgender woman” and “cisgender man.” Race/ethnicity response categories were Latino/a; African American; Asian; indigenous; white; and multiracial. Cancer diagnosis response options provided on the survey were breast, prostate, lung, colon, ovarian/endometrial, anal, lymphoma/blood cancers, and “other” cancers.

Researcher-as-instrument

One of the first authors (AA) is a queer-identified white Jewish cisgender woman who was in her last year of an Internal Medicine residency at the time of the study. The other first author (CK) is a gay-identified white cisgender man who was trained as a clinical psychologist and employed as a researcher at an academic cancer center at the time of the study. As queer-identified researchers, both AA and CK have the goal of developing interventions to decrease LGBTQ cancer care disparities and increase the quality of care LGBTQ patients with cancer receive. In order to address potential bias and clarify their stance related to the content, they kept journals of their preconceptions before and during the data analysis process, and both researchers independently reviewed the data. Neither of them knew the participants in the study. Standard qualitative methods were used to ensure credibility, transferability, dependability, and confirmability, all described by Morrow as aspects of scientifically rigorous qualitative research that parallel internal validity, external validity, reliability and objectivity of quantitative research. [13, 14]

Data analysis

Data were culled from the qualitative survey items described above. The coders independently reviewed approximately 10 pages (or 1/8) of the data, using open coding in Microsoft Excel to generate greater than 50 codes each. The researchers grouped and refined these collaboratively to create a code book, then coded a small portion of the data together to ensure that codes were consistently applied. Afterward, the researchers independently coded the entire data set. They collaboratively refined and grouped codes into categories. The entire data set was then reviewed again and coded independently by the researchers until data saturation (i.e., no new codes) was reached. Two outside auditors (ML and LM) reviewed the data to assess whether themes aligned with the quotes from participants; further clarification of themes was made with their feedback. The data presented here includes the final set of themes along with illustrative quotes, which have been minimally edited for readability. Given the anonymity of the survey, participants were not provided with an opportunity to review the findings.

Results

Participant characteristics

The majority of the participants identified as white (87.5%, *n* = 239) and as cisgender women (44.3%, *n* = 121) or men (50.9%, *n* = 139), with smaller numbers identifying as transgender (3%, *n* = 9) or other (0.7%, *n* = 2). Of the cancers assessed in the survey, breast cancer was the most commonly reported type (24.5%, *n* = 67), although 31.9% (*n* = 87) of the sample had been diagnosed with cancers other than the choices provided. The mean number of years since diagnosis was slightly over 7. There were no significant demographic or clinical differences between the 273 participants who responded to the qualitative items and the 38 participants who began the survey but did not respond to these items (see Table 1 for additional participant demographic and clinical characteristics).

Themes

Five primary themes emerged regarding the experiences of LGBTQ patients with cancer. LGBTQ patients with cancer (1) are affected by providers' LGBT-specific knowledge and skills, assumptions about sexual orientation and gender identity, and mistreatment; (2) negotiate disclosure versus concealment of identities based on the safety of clinical encounters; (3) have differing experiences based on multiple intersecting identities; (4) report more effective care when people in their support networks are included; and (5) are self-advocates and undergo transformative experiences in the face of morbidity and marginalization. We present participants' experiences categorized by theme, followed by recommendations offered by participants.

Table 1 Demographic characteristics of the current sample (*N* = 273)

Gender identity	*n* (%)
Cisgender woman	121 (44.3)
Cisgender man	139 (50.9)
Transgender woman	2 (0.7)
Transgender man	7 (2.6)
Other	2 (0.7)
Did not specify	2 (0.7)
Sexual orientation	*n* (%)
Lesbian	103 (37.7)
Gay	132 (48.4)
Bisexual	21 (7.2)
Heterosexual	8 (2.9)
Asexual	5 (0.3)
Did not specify	4 (1.5)
Race/ethnicity	*n* (%)
Latino/a	11 (3.8)
Asian	2 (0.7)
Indigenous	2 (0.7)
African American	3 (1.1)
White	239 (87.5)
Multiracial	10 (3.7)
Did not specify	4 (2.2)
Partner status	*n* (%)
Partnered	178 (65.3)
Single	92 (33.7)
Did not specify	3 (1.1)
Cancer type	*n* (%)
Breast	67 (24.5)
Lymphoma/blood	48 (17.6)
Ovarian/endometrial	21 (7.7)
Prostate	23 (8.4)
Colon	13 (4.8)
Anal	7 (2.6)
Lung	3 (1.1)
Other	87 (31.9)
Did not specify	4 (1.5)
Years since diagnosis	
Mean (range)	7.06 (0–36 years)
Location	
U.S. urban	171 (62.6)
U.S. rural	19 (7.0)
U.S. suburban	66 (24.2)
Outside the USA	14 (5.1)
Did not specify	3 (1.1)

LGBTQ knowledge, skills, and assumptions Providers' assumptions, mistreatment, and lack of LGBTQ-specific knowledge and skills were reported by participants, as well as instances in which providers' knowledge and skills led to improved patient-provider interactions. A white, cisgender lesbian wrote,

> I had been sick for a year prior to diagnosis but my primary care doctor kept trying to get me to take anxiety medication and treating my shortness of breath as panic attacks instead of a result of the large tumor in my chest which would later be found. I feel a lot of that had to do with pre-conceptions about gay people.

Experiences varied considerably based on the specific LGBTQ identities of participants; in particular, transgender patients experienced unique types of mistreatment from providers. One white, bisexual transgender man implied that his experience with healthcare providers considerably worsened after transition. He wrote, "Prior to [transition] I lived as a lesbian female for 50 years and never once experienced any hostility or discrimination by any health care provider. I was never denied care, interrogated, distrusted, or treated with overt hostility and rejection. Transitioning changed all that." Participants also described providers' misgendering—using a name, pronoun, or something else that implies the incorrect gender identity—of patients and their support people. A white bisexual transgender man wrote, "I haven't been through a legal name change, so all of my insurance info and charts are in my old name. Some of the doctors and nurses were able to remember my chosen name, but others weren't..."

Participants also described the ways lack of knowledge could lead to mistreatment or affect patient provider relationships. A cisgender Latina lesbian who identified as "butch" noted her provider's assumption that "the dilator is merely uncomfortable," explaining, "not all lesbian women have had their body cavities opened and painfully examined." Her provider's assumption led to a painful examination. By contrast, a white cisgender gay man described an encounter in which provider knowledge improved his treatment, writing, "my radiologist... used terms that indicated an understanding of gay men's sexual behavior, for example he asked who was the top and who was the bottom."

Recommendations Participants made recommendations for providing relevant care and support services based on patients' genders. Transgender participants emphasized the importance of providing transition-related surgeries and hormones in the context of cancer care. A white heterosexual transgender man wrote, "I was given a total, bilateral mastectomy with male chest reconstruction as a part of my treatment. This was definitely a silver lining and if you can avail your patient of something positive... be sure to make every effort to do so." Other participants wrote about the importance of providing relevant resources for patients. A white cisgender lesbian wrote, "When I was crying in her office, a well-meaning oncology social worker suggested I go to a makeup class called 'Look Good, Feel Better.' I told her 'I'm a kind of butch lesbian. I just don't understand that stuff.'"

Participants provided suggestions for avoiding mistreatment. A bisexual transgender woman who declined to state her race wrote, "Treat us with dignity." A white cisgender lesbian suggested that providers intervene in mistreatment of patients by colleagues: "If you observe other health care providers discriminating or treating a patient or support person with anti-gay bias - stand up and stop it!"

Disclosure and concealment Many participants reported that they were afraid to disclose their identities to their oncologists because they felt it was not safe. A Latina cisgender lesbian wrote,

> 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. Being discovered as a lesbian in a Catholic hospital can be lethal when having cancer.

Recommendations Participants offered suggestions for ways in which the care team could make coming out and being identified as LGBTQ safer. A white cisgender lesbian suggested using inclusive language. "By including the term 'partner,' the provider thus lets the patient know that being LGBT isn't going to get him/her ostracized from the medical profession." Others described the importance of providers coming out to patients. A white cisgender gay man wrote, "[One of the nurses] told me she was a lesbian, and it really made our interactions more special."

Participants also recommended avoiding assumptions of cisgender and heterosexual identities. A bisexual transgender woman who declined to state her race wrote, "Expect the unexpected. For example, don't get upset when you go to put in a Foley [catheter] and find the person is pre-op." A white cisgender woman detailed the complications surrounding assumptions of sexual orientation: "People don't always identify how they are 'read.' I was queer and married to a hetero male, but no one knew that at the time except me."

Intersectionality Multiple intersecting identities affected the care patients received. A woman shared her experiences with ageism and homophobia: "As an alone, aging senior, I am also dealing with fear of rejection by being 'out' even though I was very 'out' when younger and in a partnership." Other participants wrote about experiences wherein interactions between racism and homophobia affected the care they received. A white cisgender gay man wrote, "When I talked to the nurse about my dissatisfaction with how they treated my partner, the nurse apologized and said that he assumed that we were just friends because my partner is both African-American and younger than me." Participants also referenced the way experiences of cancer care were influenced by gender, sexuality, and financial matters. A white cisgender bisexual woman wrote, "As two women working for non-profits, our healthcare coverage was woefully inadequate."

Other participants described the ways they were unable to access resources because of the intersections of multiple axes of oppression. A white cisgender bisexual woman wrote about a policy barring Palestinian organizations from using space at an LGBTQ center: "I wish [the Center] would understand that Queer Palestinians need to use the space, too."

Recommendations To better address intersectional identities, a white cisgender bisexual woman suggested, "Consideration for the costs associated with procedures, as well as time-off, is very important." A gay cisgender indigenous man wrote, "Indian Health Services should have an oncology team ready to address patients and assure them or at least answer questions."

Support networks The importance of involving support networks in care was raised by many participants. When LGBTQ relationships were unacknowledged, this presented further barriers to quality care. A white lesbian who declined to state whether she was cisgender or transgender wrote, "Being an out lesbian in a serious monogamous relationship was not particularly an issue. In retrospect, however, I do very strongly feel that my partner's well-being as my caretaker was tremendously unacknowledged. She was generally welcomed but treated a 'friend' not a 'spouse' and care-taker." Other participants contextualized the importance of support from chosen family within the sequelae of homophobia. A white cisgender gay man wrote, "Since my biological family refuses to have any contact with me, it is essential to my health and survival that they understand that my partner IS MY FAMILY and when they treat him as such my outcomes are much better."

Recommendations Participants elaborated on the need to integrate support people who were neither partners nor biological family members, and who themselves were LGBTQ. A cisgender lesbian woman who declined to state her race elaborated, "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."

In addition to describing the supportive relationships they already had, a number of participants highlighted the importance of referrals to other support networks, particularly support groups specifically for LGBTQ patients. A white cisgender lesbian wrote, "I needed to talk to other gay women with cancer. I tried a support group for women with breast cancer. All the women were straight and THEY gave me a hard time for not doing reconstruction... I would tell them to help their LGBT clients connect with other LGBT people for support." Other participants cited reasons LGBTQ people might have unique support needs. A white cisgender lesbian explained the importance of these referrals, writing:

> An LGBT person may be estranged from their families of origin; they may not be out at work or to their families. . . For LGBT people diagnosed with cancer, the first things to ask are: "What kind of support network do you have?" and "Can I offer you information about LGBT-friendly networks?"

Self-advocacy and transformative experiences A final theme that emerged from participants' comments was that some LGBTQ patients were uniquely able to advocate for themselves and build transformative experiences in the context of cancer diagnosis and treatment. For example, a white cisgender gay man wrote, "If I had not felt that both me and my partner were fully supported by the medical team I would have immediately gone elsewhere." A white heterosexual transgender woman wrote about the techniques she employed in inpatient settings: "I quickly learned that while some nurses were incredibly kind and sympathetic, others were competent but unfriendly and disrespectful, misgendering me etcetera. I. .. had to quickly figure out which nurses and aides were going to be helpful and which weren't."

Other participants described their cancer diagnoses as transformative. Participants described providing educational opportunities about their experiences through essays and art. A white cisgender lesbian wrote, "I see the cancer diagnosis—and especially the recovery process... as a turning point in my life. I'm embracing life, loving life and, most importantly, loving myself in more ways than before.... I don't know how long I have now, but I'm delighted with life and living with gratitude."

Discussion

This qualitative study aimed to better understand the experiences of LGBTQ patients with cancer, along with their recommendations for cancer care providers. Our data demonstrated that LGBTQ patients' care is affected by providers' assumptions, opportunities for disclosure, intersecting marginalized identities, availability and integration of support, and their own self-advocacy. Although studies have explored LGBTQ patients' specific cancer-related outcomes, [2, 9, 15–18] little research has explored the recommendations that LGBTQ patients with cancer would offer providers to improve care. Considering a recent position statement on care for this population by the American Society of Clinical Oncology, this information is particularly timely. [11] The responses of LGBTQ patients in the current study detailed providers' lack of LGBTQ-specific knowledge and skills that create barriers to cancer care, confirming what has been found in previous studies of LGBTQ patients generally. [5, 19] Many LGBTQ people have negative experiences with medical providers [20–24] and fear further mistreatment. Transgender participants, in particular, detailed instances of misgendering and emphasized the importance of using patients' correct name and pronouns and the importance of providing treatments that contribute to quality of life, in line with other recent scholarship [25]. Some participants in our study had positive experiences with knowledgeable providers which may be a sign of progress.

Participants described other factors that influenced their care, such as involvement of support partners and acknowledgement of marginalized identities. Studies of LGBTQ and heterosexual patients with cancer have shown the significance of partners in the recovery process. [26, 27] In keeping with these findings, our participants wanted the people in their support network to be included in care. Participants also emphasized differences in their experiences based on the intersections of gender identity, sexual orientation, race, and other stigmatized identities. [28, 29] In particular, some participants described the ways in which multiple, often overlapping, societal systems of oppression (e.g., racist and sexist/heterosexist policies) restricted their access to resources and support.

Participants described their own self-advocacy throughout the cancer treatment process. Self-advocacy in cancer has been defined as a process of fulfilling health-related needs and goals through personal skills and action [30, 31]. However, self-advocacy may be less possible for patients who are severely ill or those with multiple stigmatized identities. [32] Given this, it is important to further explore the ways that self-advocacy is developed by LGBTQ patients with cancer so that resources and providers can better support these processes.

See Table 2 for a full list of recommendations for cancer care providers based on our findings. Many of these recommendations are in line with suggestions offered by LGBTQ patients without a history of cancer in another qualitative study [5].

The most prominent limitation of the current study was the lack of demographic variability, given that most participants were white, cisgender, and gay or lesbian. More research is needed on the experiences and recommendations of bisexual and transgender people as well as LGBTQ people of color. Additionally, demographic information was limited by the response options provided for sexual orientation, gender identity, race, and cancer type. For example, as concurrent research would later show is not uncommon [33], two transgender participants wrote that they did not identify as either of the two transgender response options. Similarly, some respondents may not have felt that any of the race/ethnicity options applied to them and this may have also limited responses. Additionally, age and income were not captured in our demographics questionnaire. Given that participants were recruited from LGBTQ-specific sources, the sample may not have included people who are sexual and gender minorities but who are not open about their identities. Finally, participants responded to open-ended questions on a survey. As this was not an in-depth interview, no follow up questions were asked and so participants were not encouraged to further expand on their recommendations. Despite these limitations, this study included a sampling frame not confined to a specific geographic area and a recruitment technique able to capture a population difficult to identify in general surveys. In addition, it captured the detailed experiences and recommendations of LGBTQ people with a history or current diagnosis of cancer, a topic little researched previously.

In future studies, collection of data on the experiences and recommendations of transgender people, gender non-binary

Table 2 Guidelines for cancer care providers based on findings

(1) Provide access to LGBTQ-specific cultural competency, responsiveness, and humility training focused for all cancer care staff and providers.

(2) Provide safe environments for disclosure by using inclusive language (on forms, brochures, websites, etc.), asking about LGBTQ identities, and responding to disclosure respectfully.

(3) Ask about and use patients' correct names and pronouns.

(4) Intervene when patients are mistreated by colleagues or when you witness lack of LGBTQ competence in care.

(5) Ask about and address the effects of cancer treatment on sexuality, applying knowledge of LGBTQ sexuality.

(6) Include support people of the patient's choosing and ensure non-discrimination in visitation policies.

(7) Avoid assumptions regarding the relationships of patients and their support people by inquiring about them. For example, ask "how is this person related to you?"

(8) Provide clinical examinations informed by knowledge of patients' sexual histories, gender identities, and anatomies.

(9) Provide transition-related surgeries and hormone therapy when relevant and possible in the context of cancer care.

(10) Provide cancer support resources that are relevant to the sexual orientation and gender identities of patients.

(11) Assess and reinforce self-advocacy, self-protection, and transformative experiences of LGBTQ patients in the context of cancer care.

people, and people of color with a history or current diagnosis of cancer are warranted. In-depth mixed methods studies that can examine both experiences of care and health disparities experienced by LGBTQ people with cancer would also add to the literature. Based on data from our large, nationwide sample, however, we believe that following these patient-driven guidelines for cancer care providers could serve as a first step toward improving health outcomes for LGBTQ people with cancer and as a jumping off point for further research, interventions, and program development.

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Compliance with ethical standards

Conflict of interest All authors report that they have no conflicts of interest to disclose.

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