

# Experiences of Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Survivors, a Qualitative Study

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## BACKGROUND

- ❖ Sexual orientation and gender identity data are rarely collected, so LGBT patients are often invisible in cancer studies.
- ❖ Experiences of LGBT cancer patients are not well-known.

## OBJECTIVES

- ❖ Investigate the experiences of LGBT patients with cancer.
- ❖ Generate patient-informed guidelines for providing quality care for LGBT patients with cancer.

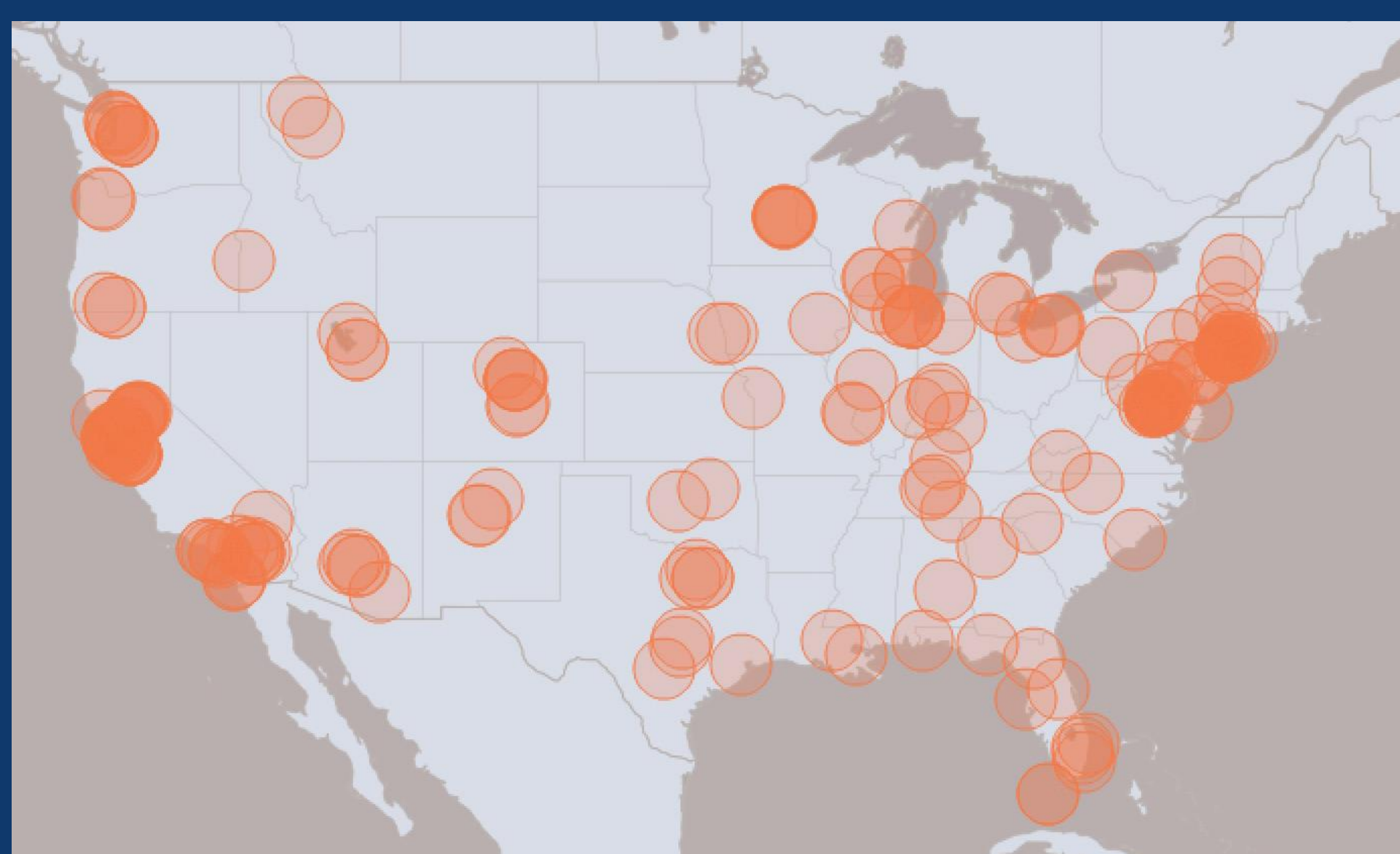
## RESEARCH DESIGN

- ❖ Participants were recruited via LGBT websites and email blasts.
- ❖ An online survey was posted to Zoomerang January to April, 2012
- ❖ The survey included two open-ended prompts:
  1. *If you were to give a class to healthcare workers, focused on cancer care, what would you tell them about being LGBT and being diagnosed with cancer?*
  2. *If there is anything else you would like to add about your experience of being diagnosed with cancer, please write it here:*
- ❖ See Table 1 for demographic characteristics of participants.

**Table 1: Sample demographic characteristics**

Characteristic	Total Sample n=307 n (%)
Race/Ethnicity	
Non-Hispanic White	255 (87.7)
Non-White/Hispanic	52 (12.3)
Marital Status	
Partnered/Dating	189 (64.9)
Single/Separated	102 (35.1)
Cancer type	
Breast	69 (23.7)
Lymphoma/Blood	56 (19.2)
Ovarian/Endometrial	20 (6.9)
Prostate	22 (7.6)
Colon	13 (4.5)
Anal	10 (3.4)
Other	101 (34.7)
Years since diagnosis	
Mode (range)	3 (0-36 years)
Mean (s.d.)	7.06 (6.50 years)

**Figure 1: Geographic distribution of respondents**



## RESULTS

**Table 2: Themes and illustrative quotes**

1. Mistreatment, assumptions, and gaps in providers' knowledge and skills, create obstacles to quality care.	2. LGBT patients desire safe encounters in which to disclose identities.	3. Health outcomes for LGBT patients are improved when support people are included	4. Experiences differ based on multiple intersecting identities.	5. LGBT patients with cancer are resilient in the face of morbidity and marginalization
Expect the unexpected, i.e. don't get upset when you go to put in a Foley [catheter] and find out the person is pre-op.	My partner did not come to the hospital because I didn't want my treatment compromised. An anti-gay surgeon could easily "accidentally" miss one of the many small lesions of the cancer.	I want [providers] know how much I relied on my partner for love and support and how much [her presence] helped me navigate my way through cancer treatment.	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."	I see the cancer diagnosis as a turning point in my life. I don't know how long I have now, but I'm delighted with life and living with gratitude.

## DATA ANALYSIS

- ❖ Researchers utilized an interpretivist paradigm, which acknowledges that meaning is constructed and contextual.
- ❖ Independently, two researchers conducted open coding
- ❖ Codes were clustered and refined and a code book was generated.
- ❖ Data were again independently coded; final themes were defined.

## RECOMMENDATIONS

- ❖ Given that patients may not be easily identifiable as LGBT, particularly if they are in opposite-gender relationships, inquire about all patients' gender identities and sexual orientations.
- ❖ Create inclusive intake forms and pamphlets.
- ❖ Ensure safety and ongoing quality care after patients come out.
- ❖ If you are LGBT, consider coming out to patients.
- ❖ Inquire about support people using inclusive language, welcome support people, acknowledging LGBT partners as such and providing them with information and support.
- ❖ Acknowledge interracial families and relationships.
- ❖ Be comfortable with LGBT patients and be able to discuss sexual behavior in the context of treatment.
- ❖ Maintain and provide patients with LGBT-specific resources.
- ❖ Be aware of financial barriers to care, including the need for time off from work, and mitigate them whenever possible.
- ❖ Provide financial, housing, and other resources to patients
- ❖ Understand the clinical implications of co-morbid HIV and cancer.
- ❖ Use patients' preferred names and pronouns.
- ❖ When possible, provide gender-confirming surgeries in the context of cancer care and continue hormone therapy.
- ❖ Provide a range of post-mastectomy options including reconstruction of a male-appearing chest.
- ❖ Acknowledge the resilience of patients in the face of cancer.

## CONCLUSIONS

- ❖ LGBT cancer survivors report obstacles to accessing competent cancer treatment.
- ❖ To address this, providers could use inclusive language, inquire about patients' identities, and include chosen support people.
- ❖ Learning about diverse LGBT communities may decrease assumptions.
- ❖ Acknowledging the resilience of LGBT cancer survivors may improve relationships with patients.

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