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Representation of lesbian, gay, and bisexual people in clinical cancer trials

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Abstract

Purpose—Clinical trials are important tools for advancing cancer treatment, prevention, and control. To identify and describe clinical effects relevant to underserved groups, their representation in clinical trials is necessary. Lesbian, gay, and bisexual (LGB) people have been identified as a medically underserved group and their representation in cancer clinical trials is unknown. This study sought to examine LGB cancer survivor representation in cancer clinical trials.

Methods—Data were from the 2010, Behavioral Risk Factor Surveillance System, Cancer Survivorship Module. Data were from five states that included both the Cancer Survivorship module and an item asking self-identified LGB status.

Results—Participation in cancer clinical trials was higher among LGB cancer survivors (12.5%) than among heterosexual cancer survivors (6.0%) ($p = .005$). In the multivariate, adjusted model, LGB cancer survivors were more than twice as likely, as heterosexual cancer survivors, to report participation in a clinical trial (AOR 2.17, 95% CI 1.21–3.90).

Conclusion—LGB cancer survivors had greater likelihood of cancer clinical trial participation than heterosexual cancer survivors and this was not explained by demographics. The finding was unexpected given the historic marginalization of this group. The small number of LGB cancer survivors limits the generalizability and statistical power. Findings should be interpreted cautiously, and further research is needed to clarify explanatory mechanisms.

Keywords

Clinical cancer trials; Gay/lesbian/bisexual; Cancer survivors

Introduction

Medically underserved populations, such as racial/ethnic minorities, underinsured or uninsured groups, those with low levels of education, and those with low income [1], have been underrepresented in cancer prevention and control clinical trials [1,2]. To identify and describe relevant clinical effects, representation of medically underserved cancer survivors in clinical trials is necessary [1]. Medically underserved populations also include lesbian, gay, and bisexual (LGB) people [3], yet almost nothing is known about the representation of LGB cancer survivors in cancer clinical trials. In the only publication regarding LGB

clinical trial representation, in 15% of clinical trials funded by the National Institutes of Health, authors reported the explicit exclusion of LG people [4], but they did not report on cancer clinical trials. Currently, there are no estimates of the representation of LGB cancer survivors in clinical cancer trials.

Therapeutic trials databases and population-based cancer registries that inform clinical trial recruitment and accrual do not record information concerning participants' sexual orientation [5]. Consequently, determining LGB representation in cancer clinical trials requires alternative approaches, such as leveraging existing, population-based data sources that include information about cancer clinical trial participation, cancer survivorship, and sexual orientation [6]. The use of such data offers preliminary information about the representation of LGB cancer survivors in cancer clinical trials. The purpose of this study was to describe the representation of LGB cancer survivors in clinical cancer trials. It was hypothesized that representation in clinical trials would be lower among LGB cancer survivors than heterosexual cancer survivors.

Materials and methods

The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing, probability-based, cross-sectional, health surveillance program sponsored collaboratively by the Center for Disease Control and Prevention and U.S. states and administered to samples of noninstitutionalized adults older than 18 years of age. Data were from five states' 2010 BRFSS surveys that included both the optional Cancer Survivorship module [7] and an item asking self-identified LGB status to either their entire survey population (Massachusetts, New Mexico, Wisconsin, and Alaska) or to one or more probability-based sample splits (California) (n = 4339).

Variables

Cancer survivors answered "yes" to the following item: "Have you ever been told by a doctor, nurse, or other health professional that you had cancer?" Representation in clinical trials was determined from the single question "Did you participate in a clinical trial as part of your cancer treatment?" Responses were dichotomous. Across the five states, there was slight variation in sexual minority status question wording, but response options were similar: heterosexual, gay or lesbian, bisexual, or other. Responses were dichotomized (lesbian, gay, and bisexual vs. heterosexual). Demographic characteristics included race/ethnicity (white non-Hispanic vs. non-white/Hispanic), gender (male vs. female), age (in years), education (high school diploma or less and attended at least some college), and current insurance coverage (yes vs. no).

Analysis

Bivariate analyses of demographic and clinical trial representation variables were examined by LGB/heterosexual status. A multivariate logistic regression model was constructed to examine the association between LGB status and clinical trial representation while adjusting for demographic information and survey state. We handled missing data by excluding cases without complete data, and all analyses were conducted with Stata/SE ver. 12. This project was approved by the University of Rochester Institutional Review Board.

Results

Representation in clinical cancer trials was greater among LGB cancer survivors (12.5%) than among heterosexual cancer survivors (6.0%; $P = .005$). In the multivariate model, adjusted by age, sex, education, race/ethnicity, current insurance coverage, and survey state,

LGB cancer survivors were more than twice as likely as heterosexual cancer survivors to report participation in a clinical trial (adjusted odds ratio, 2.16; 95% confidence interval, 1.20–3.88; Table 1).

Discussion

LGB cancer survivors had a greater likelihood of cancer clinical trial representation than heterosexual cancer survivors, and this association was not explained by education. This finding was unexpected, given the historic marginalization of this group [3] and previous evidence of explicit exclusion in some clinical trials [4].

It is not yet clear why LGB cancer survivors had a greater likelihood of clinical trial participation. Some have suggested that cancer patients may become motivated to participate in clinical trials when anticancer treatment options are limited by aggressive, rare, or late stage diagnosed, cancers [8]. If LGB people are more likely to experience aggressive or rare forms of cancer or are diagnosed at later stages than heterosexual cancer survivors, they may be more inclined to participate in a clinical trial. The data necessary to test this hypothesis are not available in the BRFSS, but this is a logical next step for future research.

Limitations must be noted. First, the number of LGB cancer survivors was small, which limited generalizability and statistical power. Second, although a probability-based sample, the analyses are unweighted. Per guidance from the Center for Disease Control and Prevention regarding the use of small subgroups of respondents ($n \leq 50$) from the BRFSS, analyses are unweighted [9]. Third, the self-identity measure of sexual orientation may introduce bias in identifying persons who are more willing to disclose their sexual orientation, and alternative measures of sexual orientation (eg, same-sex behavior or attraction) may produce different results.

This study is a first step toward understanding the representation of LGB cancer survivors in cancer clinical trials. The representation of LGB cancer survivors in clinical cancer trials is important for innovation and improvements in health care delivery to underserved groups. Further research is needed to confirm estimates of the representation of LGB cancer survivors in clinical cancer trials and to clarify the explanatory mechanisms of potential differential participation.

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Table 1

Bivariate and multivariate results among cancer survivors by sexual minority status

	Bivariate analysis		P	Multivariate analysis
	Sexual minority (n = 127), n (%)	Heterosexual (n = 3918), n (%)		Participated in clinical trial (n = 3395) AOR (95%CI)
Demographics				
Age (mean, SE)	62.3 (1.14)	66.2 (.21)	<.001	0.98 (0.97–0.99) [*]
Sex				
Female	66 (52.0)	2507 (64.0)	.006	1.17 (0.86–1.58)
Male [†]	61 (48.0)	1411 (36.0)	—	—
Current insurance coverage				
No	6 (4.7)	115 (2.9)	.245	1.24 (0.60–2.55)
Yes	121 (95.3)	3801 (97.1)	—	—
Education				
At least some college	102 (80.3)	2653 (67.8)	.003	1.10 (0.80–1.51)
High school diploma or less [†]	25 (19.7)	1261 (32.2)	—	—
Race/ethnicity				
Non-white/Hispanic	21 (16.7)	503 (13.0)	.225	1.37 (0.92–2.05)
White, non-Hispanic [†]	105 (83.3)	3377 (87.0)	—	—
Sexual orientation				
Sexual minority	127 (2.9)	—	—	2.16 (1.20–3.88) [*]
Heterosexual [†]	—	3918 (90.3)	—	—
Participated in a clinical trial	14 (12.5)	201 (6.0)	.005 [*]	—

AOR = adjusted odds ratio; CI = confidence interval; SE = standard error; percentages may not equal 100% due to missing data.

^{*} $P < 0.05$.[†] Reference category for multivariate models.