

# Social Support, Self-Rated Health, and Lesbian, Gay, Bisexual, and Transgender Identity Disclosure to Cancer Care Providers

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Lesbian, gay, bisexual, and transgender (LGBT) patients with cancer are often invisible in cancer studies conducted in the United States (Bare, Margolies, & Boehmer, 2014). Large, nationwide cancer registries do not collect data on sexual orientation, making identification of these patients difficult or impossible (Howlader et al., 2010). Cancer-related clinical trials do not routinely ask about sexual orientation or about partnerships with individuals of the same sex despite a relatively high participation of LGBT people in these trials (Jabson & Blosnich, 2012). Prior to the introduction of the Affordable Care Act, it may have been difficult for LGBT patients with cancer to receive appropriate medical coverage (Greenesmith, Cray, & Baker, 2013). Even in oncology practice, sexual orientation and same-sex partnerships may not be recorded in the medical record (Institute of Medicine, 2011).

The few studies that have specifically sampled LGBT patients with cancer (Boehmer, Glickman, Winter, & Clark, 2013) or have used national databases that assess sexual orientation (Kamen et al., 2014) have indicated that the experience of cancer diagnosis and treatment may be quite different for LGBT patients than for heterosexual patients. LGBT identity disclosure, for example, is a unique factor that influences care of LGBT patients. Katz (2009) found that gay and lesbian patients have considerable difficulty disclosing their sexual identity to cancer care providers. Additional studies of disclosure to cancer care providers have indicated that lesbian and bisexual patients with breast cancer may not disclose their orientation when providers do not ask (Boehmer & Case, 2004) and that they have poorer perceptions of the medical care they received than their heterosexual counterparts (Fobair et al., 2001). Noncancer studies indicated that older LGBT patients in particular have difficulty disclosing their identity to medical providers (Brotman, Ryan, & Cormier, 2003) and that lack of disclosure results in poorer health outcomes for LGBT patients of all ages (Durso & Meyer, 2013). Unfortunately, many of the studies of disclosure in the context of cancer care

**Purpose/Objectives:** To describe factors related to diagnosis, identity disclosure, and social support among lesbian, gay, bisexual, and transgender (LGBT) patients with cancer, and to explore associations between these factors and self-rated health.

**Design:** Cross-sectional self-report survey design using descriptive and exploratory multivariate statistical approaches.

**Setting:** Online, Internet-based.

**Sample:** 291 LGBT patients (89% Caucasian; 50% gay, 36% lesbian, 7% bisexual, 3% transgender) with mixed cancers.

**Methods:** Participants completed a researcher-designed online survey assessing experiences of cancer diagnosis among LGBT patients at a single time point.

**Main Research Variables:** Demographics, which provider(s) delivered the patients' cancer diagnoses, to whom patients had disclosed their LGBT identity, how they disclosed, who was on their social support team at the time of diagnosis, and current self-rated health.

**Findings:** 79% of participants reported disclosing their identities to more than one cancer care provider. Participants most commonly introduced the topic of LGBT identity themselves, sometimes as a way to correct heterosexual assumptions (34%). Friends were the most common members of LGBT patients' support teams (79%). Four disclosure and support factors were consistently associated with better self-rated health.

**Conclusions:** Disclosure of LGBT identity is a common experience in the context of cancer care, and disclosure and support factors are associated with better self-reported health among LGBT patients.

**Implications for Nursing:** Creating safe environments for LGBT patients to disclose could improve cancer care delivery to this underserved population. Nurses and other providers should acknowledge and include diverse support team members in LGBT patients' care.

**Key Words:** cancer; sexual orientation; health disparities; social support

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have focused solely on lesbian and bisexual women (St Pierre, 2012); a need exists for research that examines a

range of factors related to disclosure among LGBT patients with cancer more broadly.

The presence of same-sex partners at cancer care appointments has been closely linked to disclosure of sexual identity and anxiety about this disclosure. Katz (2009) found that the gay and lesbian patients in her study were concerned about the acceptance and inclusion of their same-sex partners by the cancer care team. Same-sex partners are a primary source of support for LGBT patients (White & Boehmer, 2012), but LGBT patients may also rely on unique social networks that incorporate friends, ex-partners, and families of choice (Grossman, Daugelli, & Hershberger, 2000). Involvement and inclusion of these support sources is important in promoting positive health outcomes among LGBT patients because social support across sources is associated with better quality of life and functioning among lesbian and bisexual patients (Arena et al., 2006; Boehmer et al., 2013; Boehmer, Freund, & Linde, 2005) and possibly among LGBT patients broadly. Inclusion of LGBT support systems is highlighted as a best practice for nurses and other providers working with this patient population (Lim, Brown, & Justin Kim, 2014).

Given the link between disclosure of sexual identity, incorporation of diverse support sources, and health outcomes among LGBT patients, the current study assessed a range of environmental and social factors related to disclosure by LGBT patients with cancer and linked these factors to self-rated health. The goals of these analyses were to provide descriptive statistics and to give an initial perspective on long-term associations between factors surrounding diagnosis and later self-rated health. Consequently, the specific objectives of this study were (a) to describe demographic and diagnosis-, disclosure-, and social support-related factors among LGBT cancer survivors reflecting on their experience of receiving a cancer diagnosis; and (b) to explore associations between these factors, recalled from the time of diagnosis, and self-rated health reported at the time of the survey.

## Methods

This study was approved by the institutional review board of California State University, San Bernardino. The study instrument used in the current study is a 28-item questionnaire, designed by the research team to be answered online, that assesses sociocultural aspects of coping with a cancer diagnosis. The study was designed from the outset to be primarily descriptive and exploratory. Items were quantitative and qualitative and were framed retrospectively to assess self-reported experiences at the time of diagnosis with some exceptions. Survey items were derived from the general comfort questionnaire from the comfort theory (Kolcaba, 1992; Kolcaba & Steiner, 2000) in

consultation with Kathy Kolcaba, MD, and content experts from the National LGBT Cancer Network ([www.cancer-network.org](http://www.cancer-network.org)). The authors of the current article present findings from the quantitative items.

Participants were recruited through LGBT-specific websites, including blogs, newsletters, and other media. Inclusion criteria were that the participant self-identified as LGBT and had been diagnosed with cancer. The online survey was posted through Zoomerang™ from January 25, 2012, to April 4, 2012.

## Participants

For the current study, the analytic sample was restricted to only those respondents who provided data on all items. A total of 311 participants began the survey, but only 291 provided complete data on all demographic, diagnosis, disclosure, support, and self-rated health items. The final sample included these 291 adult LGBT cancer survivors.

## Measures

**Demographics:** Demographic items assessed gender identity at time of diagnosis, sexual orientation at time of diagnosis, race, relationship status at time of diagnosis, primary site of most recent cancer diagnosis, and year that the LGBT participant was most recently diagnosed with cancer.

**Diagnosis-related factors:** One item assessed which type of cancer care providers delivered the cancer diagnosis, allowing participants to select any provider who was in the room when the diagnosis was delivered. Response options were family or primary care provider, nurse or nurse practitioner, oncologist, radiologist, surgeon, or social worker.

**Disclosure-related factors:** One item assessed to which cancer care providers the participant had disclosed LGBT identity, again allowing participants to select any provider to whom they had disclosed. Response options were family or primary care provider, nurse, oncologist, radiologist, surgeon, social worker, or clerical staff.

Another item assessed how participants had disclosed their LGBT identity to their cancer care providers, allowing participants to select any options that applied. Paraphrased response options were, "The clinic's intake form gave me the opportunity to disclose," "The provider asked me a direct question about my identity," "I brought up the subject myself (including as a way to correct a mistaken heterosexual assumption)," "Someone else told the provider," or other.

**Support-related factors:** A pair of items assessed who was part of the patient's social support team at the time of diagnosis and who else was in the room when the diagnosis was delivered. Participants could select any options that applied. Both items had the same response

options: partner at the time, ex-partner, friend, parent, sibling, other family member, or work colleague.

**Self-rated health:** One item asked the participants to rate their general health at the time they completed the survey, using a five-point Likert-type scale from poor to excellent, with an additional option for “in the final stages of my life.” Meta-analysis has shown that single-item self-rated health, using the same scale that was used in the current study, predicts mortality (DeSalvo, Bloser, Reynolds, He, & Muntner, 2006). Following the recommendations of this meta-analysis, the authors dichotomized the current self-rated health variable and examined whether demographic, diagnosis, disclosure, and social support factors, recalled from the time of diagnosis, were associated with reporting good, very good, or excellent health (coded as 1) versus reporting fair or poor health or being in the final stages of life (coded as 0) at the time of the survey.

## Data Analysis

The aim of this study was to provide descriptive and exploratory statistics to promote future research. The authors examined demographic, diagnosis, disclosure, support, and self-rated health factors descriptively, using percentages and summary statistics (e.g., means, standard deviations) where appropriate. The authors also examined associations between demographic factors and disclosure, support, and self-rated health factors using chi-square analyses.

To provide an initial perspective on long-term associations between these factors and current self-rated health, two exploratory statistical methods were used. First, the authors identified a subset of prognostic factors associated with good or better health using forward stepwise conditional logistic regression. The criterion for entering the model was a significance level of  $p < 0.05$ , and the criterion for retention in the model was a significance level of  $p < 0.1$ . The authors observed the classification matrix for the final model to assess model fit. Second, the authors used a tree analysis (Su et al., 2011) with chi-squared automatic interaction detector as the supervised tree-growing technique. This technique identifies optimal splits for each decision branch (node) using Bonferroni adjusted chi-square  $p$  values as the splitting criteria and was limited to five levels of nodes. The authors used 10-fold cross-validation to aid in tree size determination and observed the classification matrix to assess model fit. All analyses were conducted with SPSS®, version 20.0.

## Results

### Participant Characteristics

The sample consisted of 159 self-identified males, 123 self-identified females, 7 transgender female-to-male

individuals, and 2 transgender male-to-female individuals (see Table 1). Commensurate with this gender breakdown, 54% of participants ( $n = 156$ ) identified as gay and 38% ( $n = 110$ ) identified as lesbian. The majority (88%,  $n = 255$ ) identified their race as non-Hispanic Caucasian, with smaller percentages of other racial and ethnic groups. A total of 150 participants reported living with their partners, 28 were partnered but not cohabiting, 11 were just dating their partners, 93 were single, and 9 had recently separated from their partners.

Breast cancer was the most commonly reported cancer type (24%,  $n = 69$ ), but 35% ( $n = 101$ ) of the sample had been diagnosed with less common other cancers, which were not further described in the survey. The mode of the year of diagnosis reported by participants was 2009, but the mean number of years since diagnosis was slightly over seven, indicating that this sample was, on average, several years into survivorship.

### Diagnosis and Disclosure Factors

A total of 66% ( $n = 193$ ) of the sample reported that only one of the providers listed in the survey was present for the delivery of the cancer diagnosis, but 0.3%

**Table 1. Participant Characteristics (N = 291)**

Characteristic	Mode	Range	$\bar{X}$	SD
Years since diagnosis	3	0–36	7.06	6.5
Characteristic			n	%
<b>Gender identity</b>				
Male			159	55
Female			123	42
Transsexual female-to-male			7	2
Transsexual male-to-female			2	1
<b>Sexual orientation</b>				
Gay			156	54
Lesbian			110	38
Bisexual			21	7
Heterosexual			3	1
Asexual			1	< 1
<b>Ethnicity</b>				
Non-Hispanic Caucasian			255	88
Hispanic or Latino			11	4
Non-Hispanic African American			3	1
Native American			2	1
Asian or Pacific Islander			1	< 1
Other or multiracial			19	7
<b>Marital status</b>				
Partnered or dating			189	65
Single or separated			102	35
<b>Cancer type</b>				
Breast			69	24
Lymphoma or blood			56	19
Prostate			22	8
Ovarian or endometrial			20	7
Colon			13	5
Anal			10	3
Other			101	35

**Table 2. Diagnosis- and Disclosure-Related Factors (N = 291)**

Provider	Delivered Diagnosis		Patient Disclosed Identity	
	n	%	n	%
Clerical staff	–	–	99	34
Nurse	20	7	124	43
Oncologist	51	18	130	45
Primary care provider	64	22	213	73
Radiologist	15	5	48	17
Social worker	5	2	40	14
Surgeon	93	32	138	47

How did LGBT identity disclosure occur?	n	%
I brought up the subject myself (i.e., to correct assumptions).	150	52
Forms gave me the opportunity to disclose.	49	17
The provider asked me a direct question about my identity.	43	15
Someone else told the provider my identity.	7	2
Other	57	20

Note. Participants were allowed to choose more than one response, so percentages may not total 100.

(n = 1) reported that four providers were present (see Table 2). Surgeons were the most likely to be present for the delivery of the patient's cancer diagnosis (32%, n = 93), and social workers were least likely to be present (2%, n = 5). This low latter percentage is likely because of the fact that not all patients with cancer have direct contact with a social worker. Nurses were present for delivery of the diagnosis for only 7% (n = 20) of the participants.

A total of 79% (n = 230) of the sample reported disclosing to at least one cancer care provider, and 6% (n = 16) reported disclosing to all seven types of providers listed in the survey. LGBT patients were most likely to disclose identity to primary care physicians (73%) and least likely to disclose to social workers (14%). Again, this low reported percentage is likely because of lack of contact with a social worker, and this item may be a proxy for referral to social work services. Although surgeons were most likely to be present for the diagnosis, less than half of patients had disclosed their LGBT identities to their surgeons (47%, n = 138).

Participants most commonly disclosed their LGBT identity by bringing up the subject of identity themselves to correct heterosexual assumptions (52%, n = 150). Few participants reported that someone else had disclosed their identity (2%, n = 7), and few reported that their providers had asked questions to elicit disclosure (15%, n = 43).

In terms of associations between demographic and diagnosis- and disclosure-related factors, lesbian and

bisexual women were more likely to receive their diagnosis from radiologists than gay and bisexual men ( $\chi^2 = 11.66$ ,  $p = 0.001$ ), but gay and bisexual men were more likely to receive their diagnoses from primary care providers ( $\chi^2 = 4.23$ ,  $p = 0.03$ ). This discrepancy is likely because of the diagnosis of breast cancer by radiologists among lesbian and bisexual women. Bisexuals were less likely to disclose their identity to cancer care providers than any other sexuality group ( $\chi^2 = 16.49$ ,  $p = 0.002$ ), but same-sex partnered individuals were more likely to disclose their identity to cancer care providers than those who were not partnered ( $\chi^2 = 36.05$ ,  $p < 0.001$ ).

### Social Support Factors

On average, participants reported having 2.94 people on their social support teams at the time of diagnosis (SD = 1.58); 3% (n = 9) of the sample reported that no one was on their support team and 0.3% (n = 1) of the sample reported that all seven types of individuals listed in the survey were on their support team (see Table 3). Friends were most commonly listed as a source of support (79%, n = 229) and were listed more commonly than romantic partners (62%, n = 179) or any family member.

The majority of participants (61%, n = 177) reported that no member of their support team was present when they received their diagnosis of cancer. A partner was most commonly present when a member of the support team was with the patient at the time of diagnosis (27%, n = 79), and ex-partners were least likely to be present (1%, n = 3).

In terms of associations between demographic and support-related factors, lesbian and bisexual women were more likely than gay and bisexual men to have a romantic partner present when they received their diagnoses ( $\chi^2 = 13.23$ ,  $p < 0.001$ ). Lesbian and bisexual women were also more likely to report that a romantic partner ( $\chi^2 = 4.01$ ,  $p = 0.04$ ) and friends ( $\chi^2 = 7.25$ ,  $p < 0.001$ ) were on their emotional support teams.

**Table 3. Support-Related Factors (N = 291)**

Individual	Part of Support Team		Present for Diagnosis	
	n	%	n	%
Ex-partner	49	17	3	1
Friend	229	79	14	5
Other family member	79	27	4	1
Parent	116	40	18	6
Partner at the time	179	62	79	27
Sibling	117	40	6	2
Work colleague	88	30	5	2

Note. Participants were allowed to choose more than one response, so percentages may not total 100.

## Associations Between Demographic, Diagnosis, Disclosure, and Support Factors and Current Self-Rated Health

The majority of participants reported that their current health was rated as good or better (72%,  $n = 225$ ). No significant associations existed between current health and any demographic factor. Four variables were retained in the final stepwise logistic regression model: disclosure to a social worker, having a parent as part of the support team, having an ex-partner as part of the support team, and having a romantic partner present for delivery of the patients' cancer diagnosis. The logistic regression model containing these four variables correctly classified 18% of participants with fair or poor health and 94% of participants with good or better health, for a total of 74% of the sample correctly classified (see Table 4).

The decision tree analysis produced a final tree with five terminal nodes. The data were first split into those who did and did not have their parents as part of their support teams: 83% of those who did have their parents as part of their support teams reported good or better health, and 17% reported fair or poor health. Those who did not have their parents as part of their support teams were split into those who did and did not have their ex-partners as part of their support teams. Those who did have their ex-partners as part of their support teams were further split into those who had and had not disclosed their LGBT identity to a social worker (likely a proxy for those who have been referred to a social worker). One-hundred percent of those who had disclosed to a social worker reported fair or worse health, and 67% of those who had not disclosed to a social worker reported good or better health. Those who did not have their ex-partners as part of their support teams were further split into those whose partners were and were not present for delivery of the cancer diagnosis; 84% of those whose partners were present for diagnosis reported good or

better health, and 68% of those whose partners were not present for diagnosis reported good or better health. The decision tree model containing these five terminal nodes correctly classified 10% of participants with fair or poor health, and correctly classified 100% of participants with good or better health, for a total of 77% of the sample correctly classified. See Figure 1 for the final decision tree model.

## Discussion

The objectives of this study were to provide descriptive information about diagnosis, disclosure, and social support factors among LGBT patients with cancer and to conduct exploratory analyses of the association between these factors and current self-rated health. The authors also examined associations between demographic factors and the other categories of factors. This study comprises one of the largest samples of LGBT patients with cancer and survivors collected to date, and it addresses the need for additional research on the experiences of this underserved and underrepresented population.

Descriptive examination of diagnosis and disclosure factors in this study revealed that disclosure of LGBT identity is a common experience in the context of cancer care. The majority of participants in this study, 79% of the sample, had disclosed their identity to at least one provider; participants were particularly likely to have disclosed to primary care providers. Relationships between patients and primary care providers may predate the diagnosis of cancer, and LGBT people may spend time selecting primary care providers who are known to be understanding of LGBT-specific issues (Labig & Peterson, 2006). Selection of cancer care specialists, by contrast, may be restricted by geography, availability, or the nature of the cancer diagnosis. Relationships with these specialist providers may also be more limited in duration than relationships with primary care providers, further reducing the likelihood that LGBT survivors will disclose their identity. Because, in many cases, the primary care provider was not present when participants in the current study received their cancer diagnoses, LGBT patients may generally receive their diagnoses from an individual or team who does not know about their identity. This lack of disclosure could affect satisfaction with care and patient well-being (Durso & Meyer, 2013).

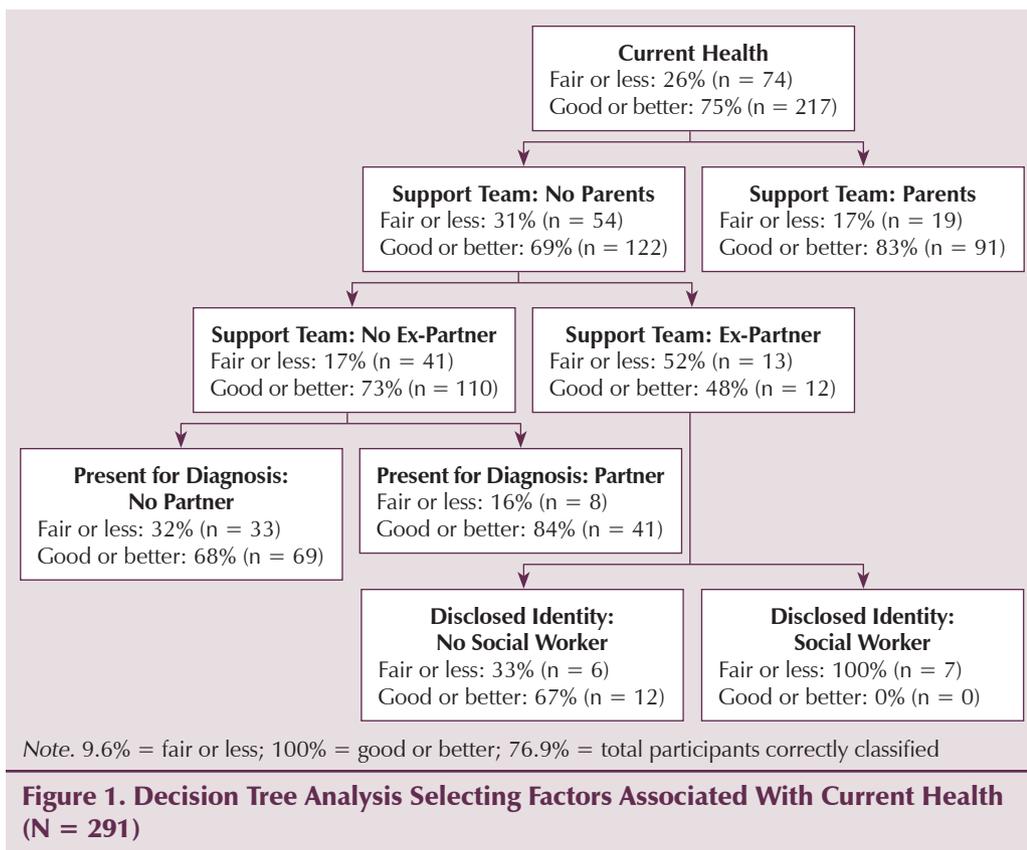
Although LGBT patients often rely on romantic partners for support, as do heterosexual patients, LGBT patients access additional social support from a wide range of sources. Of note, LGBT patients rely on friends for support more often than on family members. Because many LGBT adults have experienced alienation from their families (Ryan, Huebner, Diaz, & Sanchez, 2009),

**Table 4. Stepwise Logistic Regression Selecting Factors Associated With Current Health (N = 291)**

Factor	OR	95% CI	p
<b>Patient disclosed identity</b>			
Ex-partner	0.42	[0.21, 0.85]	0.02
Parent	2.64	[1.43, 4.87]	0.002
Part of support team	–	–	–
Social worker	0.33	[0.16, 0.71]	0.004
<b>Present for diagnosis</b>			
Partner at the time	2.82	[1.38, 5.74]	0.004

Note. 73.7% of participants were correctly classified (18.2% of those as fair or less, 93.5% of those as good or better).

CI—confidence interval; OR—odds ratio



be an artifact. Those with more complex cases, more disability, or more psychosocial needs, or those of lower socioeconomic status, may be more likely to be referred to social work. The factors that lead to a social work referral, and thereby to eventual disclosure of LGBT identity to a social worker, may be associated with poorer health over time; social work services themselves are unlikely to be the causal agent in promoting poorer current health. Social workers are also often involved in discharge planning (Haddock, 1994) and may be less involved in the process of diagnosis.

they may create a family of choice comprised of close friends. This study also confirms that LGBT cancer survivors may rely on support from ex-partners, a source often not considered when working with heterosexual populations.

The stepwise regression and the decision tree analysis found four significant associations between factors at the time of diagnosis and current self-rated health. In the decision tree analysis, support from parents at the time of diagnosis emerged as the strongest single factor associated with current good or better health. Given the alienation from family discussed previously, it may be that parental support is particularly important for LGBT patients. Having a partner present during delivery of the cancer diagnosis was also associated with better current self-reported health. This finding underscores the importance of including same-sex partners in the cancer care process because associations between this inclusion and self-rated health may be seen years post-diagnosis. Relying on support from ex-partners, by contrast, was associated with poorer current self-rated health. This finding may be an artifact of the negative impact that relationship disruption can have on health; because those with ex-partners perforce experienced the end of a romantic relationship, their health may have suffered (Glaser & Kiecolt-Glaser, 2005) and may continue to be affected. The association between disclosure to a social worker and poor self-rated health may also

## Limitations

Findings from the current study should be interpreted in light of several limitations. First, this was a researcher-created survey designed to assess areas that the research team thought were important. It did not include validated scales, and most of the items were dichotomous and descriptive. Future studies should consider using validated scales assessing a wide array of disclosure, support, and stress factors.

Second, the survey was entirely based on self-report, including self-identifying as lesbian, gay, bisexual, or transgender; self-identifying as having been diagnosed with cancer; and self-reporting current health. Future studies should sample LGBT patients with medically confirmed cancer diagnoses and assess the association of clinical characteristics, drawn from the medical record, with health and well-being.

Third, the sample was self-selected into the study; only LGBT participants who learned about the Internet survey and were comfortable disclosing their identity on this survey provided data. How generalizable this sample would be to the entire population of LGBT patients with cancer is unclear.

Finally, the statistical analyses conducted in the current study are exploratory in nature and need to be replicated with larger samples recruited with different methodologies. In particular, the regression and decision

tree analyses examined associations between self-reported factors at the time of diagnosis and self-rated health at the time of the survey, which may have been seven years or more postdiagnosis. A stronger methodology would be to examine support and disclosure factors at the time of diagnosis, and then follow LGBT patients longitudinally to observe how their health and well-being is affected.

## Implications for Nursing Practice

Oncology nurses must recognize that disclosure of LGBT identity is an important and unique factor influencing receipt of care among LGBT patients. LGBT patients self-disclosed their identity only 45% of the time to oncology providers, and 43% of the time to a nurse. Although this study is descriptive in nature, it suggests that nurses can play a particularly important role in enacting best practices for treating LGBT patients (Lim et al., 2014). Nurses can provide opportunities for disclosure of LGBT identity, and more importantly, respond appropriately and respectfully when such identities are disclosed. Nurses may also have repeated interactions with the patient and their support system. Gently querying about relationships between patients and supportive others who attend clinic visits can facilitate disclosure and involve supportive others in the process of cancer care. For example, asking a supportive other, "What's your relationship with [patient name]?" can avoid assumptions and clarify the nature of relationships early in the process of care delivery. Given the importance of social support identified in this manuscript, nurses can also screen for support needs in a respectful way. Asking, "I know this can be stressful; who do you have who can support you?" can open a dialogue with an LGBT patient about accessing diverse sources of support. This may be particularly important for LGBT patients who may not have a romantic partner or who may be alienated from their families of origin (Margolies, 2014).

## Knowledge Translation

Disclosure of sexual identity to cancer care providers and diverse support networks may be unique to lesbian, gay, bisexual, and transgender (LGBT) cancer survivors.

Disclosure and support factors present at the time of diagnosis may have a long-term impact on self-rated health among LGBT cancer survivors.

Nurses and other care providers can enact best practices to improve the cancer care experience of LGBT cancer survivors.

## Conclusions

The factors surrounding delivery of a cancer diagnosis to LGBT patients are largely distinct from factors affecting heterosexual patients. Creating safe environments for LGBT patients to disclose could improve cancer care delivery to this population, and including diverse members of an LGBT person's support team in the process of diagnosis and care has the potential to improve the health of these underserved and under-represented patients.

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