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## Sexual Minority Cancer Survivors' Satisfaction with Care

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### Abstract

**Background**—Satisfaction with care is important to cancer survivors' health outcomes. Satisfaction with care is not equal for all cancer survivors and sexual minority (i.e., lesbian, gay, and bisexual) cancer survivors may experience poor satisfaction with care.

**Methods**—Data were drawn from the 2010 LIVESTRONG national survey. The final sample included 207 sexual minority and 4,899 heterosexual cancer survivors. Satisfaction with care was compared by sexual orientation and a Poisson regression model was computed to test the associations between sexual orientation and satisfaction with care, controlling for other relevant variables.

**Results**—Sexual minority cancer survivors had lower satisfaction with care than heterosexual cancer survivors ( $B=-0.12$ ,  $SE=0.04$ , Wald  $\chi^2=9.25$ ,  $p<0.002$ ), even controlling for demographic and clinical variables associated with care.

**Conclusions**—Sexual minorities experience poorer satisfaction with care compared to heterosexual cancer survivors. Clinical Implications: Satisfaction with care is especially relevant to cancer survivorship in light of the cancer-related health disparities reported among sexual minority cancer survivors.

### Keywords

Cancer Survivorship; Sexual Orientation; Care Satisfaction

### Introduction

Ensuring the quality of healthcare delivered to the growing population of cancer survivors in the United States, and promoting survivors' satisfaction with that care, is a national public health priority (Hewitt, 2005; LiveStrong, 2004; American Cancer Society, 2014).

Satisfaction with care is critically important to cancer survivors, but is also an area of particular concern for care providers. If cancer survivors are more satisfied with the care that they receive, they will be more likely to complete prescribed cancer treatment, adhere to care providers' recommendations, and thereby receive necessary and life-saving follow up care (Jha, Orav, Zheng, & Epstein, 2008). Research that can identify groups of survivors more

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likely to experience low satisfaction could inform efforts to improve the quality of cancer care and thereby improve cancer-related health outcomes.

Satisfaction with care is traditionally understood to be multifactorial, involving effective and clear communication between providers and patients, an environment of safety and mutual respect that allows patients to disclose information, and facilitation of patients' empowerment as they participate in their own treatment and adherence decisions (Institute of Medicine, 2001). Unfortunately, perception and execution of these satisfaction-related factors may not be equal for all cancer survivors. In particular, sexual minority cancer survivors (i.e., individuals who identify as gay, lesbian, and bisexual) may experience poorer satisfaction than their heterosexual counterparts. Studies of sexual minority patients without a history of cancer indicate that these patients experience poorer satisfaction with care (Institute of Medicine, 2011). Sexual minority women (lesbian and bisexual) have reported lower satisfaction with primary care than heterosexual women (McNair, Szalacha, & Hughes, 2011); they are also 85% more likely to have unmet healthcare needs and 50% less likely to report receiving regular healthcare than heterosexual women (Heck, Sell, & Gorin, 2006). Sexual minority men (gay and bisexual) also report lower satisfaction with care than heterosexual men. Clift and Kirby (Clift & Kirby, 2012) reported that compared to 7% of heterosexual men, 12% of sexual minority men stated that a doctor did not show them respect, while 15% felt that their provider did not spend enough time with them.

Satisfaction with care might be expected to be lower among sexual minority cancer survivors than among heterosexual survivors for two primary reasons. First, due to their cancer treatment and follow-up care, sexual minority cancer survivors have extensive exposure to the healthcare system and may thereby be exposed to institutionalized heterosexism (Jillson, 2002; Institute of Medicine, 2011). Evidence published on general and family practitioners shows that most healthcare providers assume that their patients are heterosexual; 44–63% of providers are completely unaware of the presence of sexual minority patients in their practice (Dahan, Feldman, & Hermoni, 2008; Westerstahl, Segesten, & Bjorkelund, 2002). Knowledge about sexual minority health among providers is similarly limited, with 63–92% of providers reporting that they have no knowledge about health concerns and unique issues faced by sexual minority patients (Dahan et al., 2008; Westerstahl et al., 2002). Even among providers affiliated with healthcare centers recognized for sexual minority patient-centered care, knowledge about sexual minority health is minimal (Jabson, Mitchell, Doty, under review). Discrimination is also present in the healthcare setting. Over two-thirds of providers report that sexual minority patients receive poorer treatment because of their sexual orientation (Schatz, O'Hanlan, & American Association of Physicians for Human, 1994) and least one previous study has shown that sexual minority cancer survivors report experiencing discrimination during cancer treatment (Jabson, Donatelle, & Bowen, 2011).

Second, due to this institutional heterosexism and discrimination, sexual minority cancer survivors are confronted with a complex decision about whether and how to disclose their sexual identity to their cancer care providers. Previous studies have shown that gay and lesbian cancer survivors have considerable difficulty disclosing their sexual identity to cancer care providers (2009) and that lack of disclosure results in poorer health outcomes

among sexual minority patients in general (Durso & Meyer, 2013; Kamen, Smith-Stoner, Heckler, Flannery, & Margolies, in press).

Despite existing research on disclosure and its correlates, there is a dearth of evidence directly examining sexual minority cancer survivors' satisfaction with care. This issue is highly relevant to sexual minority cancer survivors because, as highlighted above, satisfaction with care is linked to treatment adherence and health outcomes. In addition, low satisfaction could be important for informing healthcare interventions to improve satisfaction and potentially for addressing documented behavioral disparities among sexual minority cancer survivors. The extent to which improving satisfaction with care might improve disparities in psychological distress (Kamen et al., 2014) and poor self-rated health (Boehmer, Miao, & Ozonoff, 2011) among sexual minority cancer survivors is yet unknown; studies must first characterize satisfaction among sexual minority populations, then use these findings to develop interventions.

Accordingly, this paper aimed to describe satisfaction with care among sexual minority vs. heterosexual cancer survivors. We hypothesized that sexual minority cancer survivors would report significantly lower satisfaction with care than heterosexual cancer survivors, even accounting for other demographic and clinical variables.

## Methods

Data for the current study were drawn from the 2010 LIVESTRONG Foundation national survey (Rechis et al., 2010). Detailed methodology for this online-only survey has been published elsewhere (Rechis et al., 2010). Approval of all survey-related procedures was obtained through the Western Institutional Review Board.

## Participants

A total of 5,106 cancer survivors who reported a personal history of cancer diagnosis provided responses to the LIVESTRONG survey and were included in analyses. Of these, 820 were receiving active treatment and 4,286 were post-treatment (ranging from less than one year to more than 5 years post-treatment). All were residents of the United States.

Participants were identified as heterosexual, lesbian, gay, bisexual, or transgender via a single self-report item. This item asked, "Do you consider yourself to be one or more of the following: Straight; Gay or Lesbian; Bisexual; Transgender; or Other." The sample of 5,106 cancer survivors included 4,899 heterosexual and 207 sexual minority survivors (gay, lesbian, and bisexual).

## Measures

The survey assessed satisfaction using seven different items. Two items directly assessed satisfaction, asking "While on treatment for cancer," and "After I finished treatment for cancer, when addressing my needs, my health care team met..." Response options for these items included, "All of my needs," "Many of my needs," "Some of my needs," "Very few of my needs," and "None of my needs." The range of responses including "All/Many/Some of my needs" was recoded as 1, and the range including "Very few/None of my needs" was

recoded as 0. Five items asked how often doctors, nurses, or other health professionals performed various supportive behaviors, including allowing time for health-related questions, giving attention to feelings and emotions, making sure the patient understood how to maintain good health, dealing with feelings of uncertainty, and involving the patient in decisions about health care. Response options for these items included, “Always,” “Usually,” “Sometimes,” and “Never.” “Always/Usually/Sometimes” were recoded 1 and “Never” was recoded 0. We combined these items into a single count scale using categorical principal components analysis, as described in the Data Analysis section.

The 2010 LIVESTRONG survey assessed demographic characteristics, other than sexual orientation, using a series of continuous and categorical items. We dichotomized categorical items to assess sex (male/female), race/ethnicity (White/non-White), age, education (high school or less/greater than high school), employment status (unemployed/employed), household yearly income (less than \$80,000/more than \$80,000), type of cancer (breast, prostate, lung, colorectal, testicular, other), type of treatment received (surgery, chemotherapy, radiation), and time since cancer diagnosis (on treatment, less than 1 year, between 1 and 5 years, more than 5 years).

## Data Analysis

We examined demographic items and each satisfaction-related item descriptively, using percentages and summary statistics (means, standard deviations) where appropriate. Factors were then extracted from the seven satisfaction-related items included in the 2010 LIVESTRONG survey using categorical principal components analysis. This technique avoids the difficulty associated with inflated shared variance between ordinal and nominal items based on shared distribution of limited response options, rather than shared content (Meulman, Van Der Kooij, & Heiser, 2004). We set the minimum eigenvalue for factor extraction at 1. We also observed the Cronbach’s alpha associated with each factor and the distribution of the resulting factors.

Finally, we checked for over dispersion; finding that over dispersion was not an issue in these data, we conducted Poisson regression to observe the relative contribution of demographic and clinical variables and sexual minority status to satisfaction with care. We used the factors identified by the principle component analysis, above, as our measure of satisfaction with care. We first evaluated demographic and clinical variables, allowing variables to enter the model if their association with satisfaction was significant at the  $p < 0.10$  level in univariate analyses. We then simultaneously entered demographic and clinical variables and sexual minority status into the Poisson model. We evaluated each factor’s weight and the overall model deviance to assess model fit. All analyses were conducted with SPSS 20.0.

## Results

### Demographic Characteristics

The sample consisted of 1,861 males and 3,245 females; of these, 86 were sexual minority (gay or bisexual) males, while 121 were sexual minority (lesbian or bisexual) females. The

majority of the sample as a whole (88.9%, n=4,538) identified their race as non-Hispanic white with smaller percentages of other racial and ethnic groups. The mean age was 48.85 (standard deviation = 14.13). A minority (5.9%, n=300) reported a high school education or less, while 63.6% (n=3,234) reported that they were employed either part or full time. A total of 40.6% of the sample (n=2,073) had a yearly household income of \$80,000 or less.

Breast cancer was the most commonly reported cancer diagnosis among LIVESTRONG survey participants in 2010 (19.3% of the sample), followed by testicular (5.3%), colorectal (4.2%), and prostate (3.8%) cancers. The majority of participants had been treated with surgery (71.6%), chemotherapy (61.7%), and/or radiation (48.2%). A total of 27% of participants had completed treatment 1–5 years previously, 27.1% had completed treatment less than 1 year previously, 17.7% of participants had completed treatment more than 5 years previously, and 8.1% were currently undergoing treatment. See Table 1 for additional demographic and clinical characteristics.

### Satisfaction with Care

Table 2 summarizes survivors' satisfaction with care stratified by sexual orientation. Across all seven items, fewer sexual minority cancer survivors reported satisfaction with care than heterosexual cancer survivors; differences on each item ranged from 3.2 to 9.5 percentage points (mean = 7.6). The largest difference was observed on item seven: "How often did they involve you in decisions about your health care as much as you wanted?" where 72% of sexual minority cancer survivors felt that they had been involved as much as they wanted, compared to 81.5% of heterosexual cancer survivors. The smallest difference in satisfaction by sexual orientation was observed on item three: "How often did doctors, nurses, or other health care professionals give you the chance to ask all health-related questions you had?" where 84.1% of sexual minority survivors reported a chance to ask questions compared to 87.3% of heterosexual survivors.

### Categorical Principal Components Analysis

Using categorical principle components analysis with variable principal normalization and retaining factors with an eigenvalue > 1, a single factor was extracted, explaining 64.4% of the total variance. As shown in Table 2, all seven items were retained in the final extracted factor. All had factor loadings greater than 0.4 with no cross-loadings. Factor loadings ranged from 0.70 ("While on treatment for cancer...") to 0.85 ("Give attention to feelings"). The resulting factor showed high internal consistency, with a Cronbach's  $\alpha$  of 0.90.

The newly formed satisfaction with care scale ranged from 0–7; the total sample's mean satisfaction with care was 4.79 (sd = 2.14). Sexual minority cancer survivors had lower satisfaction with care (mean = 4.28, sd = 2.28) than heterosexual cancer survivors (mean = 4.81, sd = 2.13;  $t=3.52$ ,  $p<0.001$ ).

### Poisson Regression

The results of the Poisson regression model are shown in Table 3. Sex, race, employment, income, breast and colorectal cancers, being on treatment, being less than one year post-treatment, or being between one and five years post treatment were allowed to enter the

model, based on their univariate association with satisfaction with care at the  $p < 0.10$  level of significance. Being employed ( $B = 0.07$ ,  $p < 0.001$ ), having an income greater than \$80,000 ( $B = -0.06$ ,  $p < 0.001$ ), being on treatment (as opposed to 5 or more years post treatment;  $B = -0.17$ ,  $p < 0.001$ ), being less than one year post-treatment ( $B = 0.11$ ,  $p < 0.001$ ) or between one and five years post treatment ( $B = 0.12$ ,  $p < 0.001$ ) were associated with higher satisfaction. Sexual orientation was negatively associated with satisfaction with care, such that sexual minority cancer survivors had poorer satisfaction with care above and beyond the effects of other demographic variables ( $B = -0.12$ ,  $p = 0.002$ ).

## Discussion

Very little is known about sexual minority cancer survivors' satisfaction with care. We hypothesized that sexual minority cancer survivors would have significantly lower satisfaction with care than heterosexual cancer survivors. Our findings supported this hypothesis: sexual minority cancer survivors reported less satisfaction with care than heterosexual cancer survivors. This finding is consonant with the limited available evidence that documents satisfaction with care among sexual minority individuals without a personal history of cancer; sexual minority individuals in general are less satisfied with their healthcare than heterosexuals (Clift & Kirby, 2012; Heck et al., 2006; McNair et al., 2011; Institute of Medicine, 2011). However, ours is the first report of sexual minority cancer survivors' satisfaction with care after cancer.

This finding may be particularly relevant to sexual minority cancer survivorship in light of the cancer-related behavioral health disparities observed among sexual minority cancer survivors after cancer. Sexual minority cancer survivors are more likely than their heterosexual counterparts to report poorer health, tobacco use, substance use, and alcohol use after cancer (Boehmer, Miao, & Ozonoff, 2012; Jabson, Farmer, Bowen, 2015; Kamen et al., 2014) and sexual minority female cancer survivors are less likely to be physically active (Boehmer, Miao, & Ozonoff, 2012) and report poorer self-rated health (Boehmer et al., 2011) after cancer. These cancer-related health behaviors are important as they can diminish quality of life, increase risk for cancer recurrence and new second primary malignancies, and elevate risk for mortality. Satisfaction with care is positively associated with cancer-survivor provider relationship, communication, and safety in the clinical setting (Institute of Medicine, 2001; Jha et al., 2008), and it is possible that sexual minority cancer survivors' low satisfaction with care could therefore diminish their access to the necessary resources that could eliminate behavioral health disparities.

Pervasive discrimination and heterosexism existing at multiple levels of the healthcare system could be one explanation for the low satisfaction observed among sexual minority cancer survivors in the current study (Institute of Medicine, 2011). Future work in this area should use rigorous methodologies and health surveillance to monitor and document sexual minority survivors' satisfaction with care. If disparities in care satisfaction are confirmed among sexual minority cancer survivors, drivers of this disparity, such as discrimination, should be identified. Such findings could be used as a guide for reducing disparities in care satisfaction by intervention development, implementation, and testing at the hospital and clinic levels.



This study is not without limitations. The LIVESTRONG study of cancer survivors involved an online convenience sample of cancer survivors. It is possible that the participating survivors were different in important ways from survivors who chose not to participate in an online study, and this may have biased our findings. For example, the average income in this sample is twice the national average. Due to the cross-sectional nature of the study temporality cannot be assessed and it is impossible to determine if cancer survivors felt more satisfied with care before or after receipt of treatment summaries or follow-up care instructions. Sexual minorities are a heterogeneous group; lesbians, gay men, and bisexual individuals may have important distinctions and health differences. It is possible that variation in satisfaction with care may exist within subgroups of lesbian/gay/bisexual cancer survivors and this variation could contribute to the distinct cancer-related disparities observed among sexual minority cancer survivors. However, due to sample size constraints we were unable to analyze by sexual minority subgroup. This problem has been reported by others (Jabson, Farmer, Bowen, 2015) and could be remedied by oversampling lesbian, gay, and bisexual cancer survivors in studies of cancer survivorship.

## Clinical Implications

Sexual minority cancer survivors are an understudied group. However, there is evidence that this group experiences cancer-related disparities after cancer in survivorship. Satisfaction with care represents one area that could be addressed to reduce such disparities. Solutions should involve multi-level approaches including trainings for providers, staff, and administrators in sexual minority health and health disparities and hospital/clinic-wide non-discrimination policies that are inclusive and affirming of sexual minority health and sexual minorities' presence in the healthcare setting. Until healthcare providers become informed about these issues, disparities in satisfaction with care among sexual minority cancer survivors will persist. Ours is among the first studies to report on sexual minority cancer survivors' satisfaction with care.

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**Table 1**

Demographic and clinical characteristics of cancer survivors (N=3,091)

Characteristic	Total Sample n=3,091	Sexual Minority n=134	Heterosexual n=2,957
<b>Gender, n (%)</b>			
Male	1,065 (34.5)	57 (42.5)	1,008 (34.1)
Female	2,026 (65.1)	77 (57.5)	1,949 (65.9)
<b>Race/Ethnicity, n (%)</b>			
Non-Hispanic White	2,715 (87.8)	117 (87.3)	2,598 (87.9)
Hispanic and non-White	376 (12.2)	17 (12.7)	307 (10.4)
<b>Age, Mean (SE)</b>	48.85 (14.13)	47.62 (11.78)	48.90 (14.22)
<b>Education, n (%)</b>			
High school or less	266 (8.6)	12 (9.0)	254 (8.6)
Some college	2,825 (91.4)	122 (91.0)	2,703 (86.8)
<b>Employment Status, n (%)</b>			
Employed part/full time	2,044 (66.1)	89 (66.4)	1,955 (66.1)
Unemployed/Retired	1,047 (33.9)	45 (33.6)	1,002 (33.9)
<b>Yearly Income, n (%)</b>			
\$0–\$80,000	1,832 (59.3)	72 (53.7)	1,770 (59.9)
\$81,000–\$121,000+	1,259 (40.7)	62 (46.3)	1,187 (40.1)
<b>Common Cancers, n (%)</b>			
Breast	745 (24.1)	24 (17.9)	721 (24.4)
Testicular	254 (8.2)	17 (12.7)	237 (8.0)
Colorectal	204 (6.6)	9 (6.7)	195 (6.6)
Prostate	157 (5.1)	8 (6.0)	149 (5.0)
Lung	63 (2.0)	2 (1.5)	61 (2.1)
Other	1,668 (54.0)	74 (55.2)	1,594 (53.9)
<b>Type of Treatment, n (%)</b>			
Chemotherapy	1,935 (62.6)	96 (71.6)	1,839 (62.2)
Radiation	1,474 (47.7)	51 (38.1)	1,423 (48.1)
Surgery	2,280 (73.8)	99 (73.9)	2,181 (73.8)
<b>Survivorship Time, n (%)</b>			
Less than 1 year	675 (21.8)	23 (17.2)	652 (22.0)
1 to 5 years	1,159 (37.5)	60 (44.8)	1,099 (37.2)
More than five years	906 (29.3)	38 (28.4)	868 (29.4)
Other/Unknown	351 (11.4)	13 (9.7)	338 (11.4)
<b>Sexual Orientation, n (%)</b>			
Heterosexual	2,957 (95.7)		
Lesbian/gay	97 (3.1)		
Bisexual	37 (1.2)		

**Table 2**

Items and factor loadings for the single satisfaction factor (N=3,091).

<b>Factor 1. 7 items, Eigenvalue = 4.51</b>	<b>Loading</b>
1. While on treatment for cancer, when addressing my needs, my health care team met...(all my needs, etc.)	.70
2. After I finished treatment for cancer, when addressing my needs, my health care team met... (all my needs, etc.)	.74
3. How often did doctors, nurses, or other health professionals give you the chance to ask all the health-related questions you had?	.81
4. How often did doctors, nurses, or other health professionals give the attention you needed to your feelings and emotions?	.85
5. How often did they make sure you understood the things you needed to do to take care of your health?	.85
6. How often did they help you deal with feelings of uncertainty about your health or health care?	.85
7. How often did they involve you in decisions about your health care as much as you wanted?	.79

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**Table 3**

Summary of multiple linear regression analyses predicting variance in satisfaction from demographic factors, sexual minority status, and receipt of treatment summaries and aftercare plans (N=3,091).

Variable	Satisfaction			
	$\beta$ Block 1	$\beta$ Block 2	$\beta$ Block 3	$\beta$ Block 4
Block 1: $R^2 = 0.02^{**}$				
Sex (Female)	-0.04	-0.04 <sup>*</sup>	-0.03	-0.03
Race (White)	0.03	0.03	0.04 <sup>*</sup>	0.04 <sup>*</sup>
Employment (Employed)	0.05 <sup>*</sup>	0.05 <sup>**</sup>	0.04 <sup>*</sup>	0.04 <sup>*</sup>
Income (>\$80,000)	0.06 <sup>**</sup>	0.06 <sup>**</sup>	0.05 <sup>**</sup>	0.05 <sup>**</sup>
Breast Cancer	0.04 <sup>*</sup>	0.04 <sup>*</sup>	0.06 <sup>**</sup>	0.06 <sup>**</sup>
Colorectal Cancer	0.03	0.03	0.03	0.03
On Treatment	0.03	0.03	0.02	0.02
<1 Year Post Treatment	0.08 <sup>**</sup>	0.08 <sup>**</sup>	0.06 <sup>**</sup>	0.06 <sup>**</sup>
1-5 Years Post Treatment	0.09 <sup>**</sup>	0.09 <sup>**</sup>	0.06 <sup>**</sup>	0.06 <sup>**</sup>
Block 2: $R^2 = 0.01^*$				
Sexual minority (SM)		-0.07 <sup>**</sup>	-0.07 <sup>**</sup>	-0.03
Block 3: $R^2 = 0.09^{**}$				
Treatment Summary			0.17 <sup>**</sup>	0.17 <sup>**</sup>
Follow-up Care Instructions			0.22 <sup>**</sup>	0.22 <sup>**</sup>
Block 4: $R^2 = 0.00$				
SM by Treatment Summary				<0.01
SM by Instructions				-0.04

Note: Final  $R^2 = 0.11$ ;

\*  $p < .05$ ;

\*\*  $p < .01$