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# Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team

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## Abstract

**Background:** Lesbian, gay, bisexual, and transgender (LGBT) patients fear being open about their identities, not receiving equal or safe treatment, and having their family and surrogates disrespected or ignored by providers.

**Objective:** To examine inadequate, disrespectful, and abusive care to patients and family due to sexual orientation or gender identity.

**Design:** A cross-sectional study using an online survey.

**Setting/Subjects:** Home and residential hospice, inpatient palliative care service, and other inpatient and out-patient settings. Subjects were 865 hospice and palliative care providers, including physicians, social workers, nurses, and chaplains.

**Measurements:** Inadequate, disrespectful, or abusive care to LGBT patients and discriminatory treatment of family and surrogates were measured.

**Results:** Among respondents, 53.6% thought that lesbian, gay, or bisexual (LGB) patients were more likely than non-LGB patients to experience discrimination at their institution; 23.7% observed discriminatory care; 64.3% reported that transgender patients were more likely than nontransgender patients to experience discrimination; 21.3% observed discrimination to transgender patients; 15% observed the spouse/partner of LGBT patients having their treatment decisions disregarded or minimized; and 14.3% observed the spouse/partner or surrogate being treated disrespectfully.

**Conclusions:** These findings provide strong evidence that LGBT patients and their families are more likely to receive discriminatory care as compared with those who are not LGBT. Disrespectful care can negatively impact the trust patients have in providers and institutions, and lead to delaying or avoiding care, or not disclosing relevant information. Partners/spouses and surrogates may be treated disrespectfully, have their treatment decisions ignored or minimized, be denied or have limited access to the patient, and be denied private time. Advocacy and staff training should address barriers to delivering respectful and nondiscriminatory care.

**Keywords:** discrimination; gay; health disparities; LGBT; palliative care; transgender

## Introduction

THE LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) community has a long history of experiencing discrimination and stigma in employment, criminal justice, housing, social services, and health care.<sup>1</sup> Despite important

recent gains in societal acceptance and visibility, culminating in the 2015 U.S. Supreme Court decision legalizing marriage equality for same-sex couples nationwide, a 2019 poll found a decline in acceptance of lesbian, gay, bisexual, transgender, and queer (LGBTQ) persons and increased reports of discrimination and hate crimes against LGBTQ persons.<sup>2</sup>

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There is scant data on the experience of LGBT patients and families in hospice and palliative care,<sup>3</sup> particularly for transgender patients.<sup>4</sup> The purpose of this study was to describe the experiences of LGBT patients and their families and friends with hospice and palliative care, including care that was inadequate, disrespectful, or abusive due to their sexual orientation or gender identity. It is estimated that there are ~2.7 million LGBT adults aged 50 years and older in the United States. Over 1 million are aged 65 years and older and this number is expected to grow as baby boomers age,<sup>5</sup> accompanied by an increase in the number of LGBT individuals who will require palliative and hospice care.

LGBT persons experience inadequate or discriminatory health care due to their sexual minority status and may be hesitant to disclose their sexual orientation and gender identity, fearing how this will be received by health care providers,<sup>6-9</sup> including being abused or neglected by care staff, especially health care aides, and not receiving equal, appropriate, or safe treatment.<sup>6,10,11</sup> This may be especially the case for older LGBT persons who came of age when homosexuality and gender variance were criminalized, dangerously stigmatized, and have experienced victimization. Although LGBT individuals want to discuss sexual orientation and gender identity with providers,<sup>12-14</sup> <25% thought they could be open with long-term care staff and 43% reported many instances of mistreatment, including harassment, inappropriate admission or discharge, restriction of visitors or proxies, and denial of care.<sup>15</sup> Among LGBT individuals of all ages, 19% reported having little or no confidence of being treated with dignity and respect in old age by medical providers.<sup>16</sup> There were 37% of LGBT adults, and 66% of gender nonbinary adults, respectively, aged 45 years and older who were concerned that their health care would be compromised due to their sexual orientation and gender identity.<sup>6</sup> Concerns about discriminatory care may lead to delaying or avoiding health care and thereby not engaging in advance care planning that is essential to effective palliative and end-of-life care.<sup>5,17</sup>

In a survey of palliative care providers, primarily physicians, 48% who identified as a sexual minority reported differences in how they had been treated by their institutions.<sup>18</sup> It is likely that institutions that discriminate against LGBT staff do the same with LGBT patients.

## Methods

### Study design

The study had a cross-sectional design and used mixed methods. An online survey was used to collect data. This study was approved by the institutional review boards at Albert Einstein College of Medicine/Yeshiva University (IRB number 2018-8750) and Fordham University (IRB number 1057).

### Sample

A volunteer sample was recruited from eight professional organizations representing chaplaincy, medicine, nursing, physician assistants, and social work. These include the American Academy of Hospice and Palliative Medicine (AAHPM), Association of Professional Chaplains (APC),

HealthCare Chaplaincy Network (HCCN), Center to Advance Palliative Care (CAPC), Hospice and Palliative Nurses Association (HPNA), Physician Assistants in Hospice and Palliative Medicine (PAHPM), and the Social Work Hospice and Palliative Care Network (SWHPN). An e-mail invitation was sent to the membership, and/or an announcement was posted on the organization's website or in their newsletter. Social workers were also notified through the SW-PALL-EOL listserv. The National Coalition for Hospice and Palliative Care, an umbrella organization that includes all of these groups, supported this study and encouraged its organizational members to participate. All palliative care team professionals and administrators of hospice and palliative care services were eligible to participate.

## Measures

**Provider awareness of serving LGBT patients.** Respondents were asked how many of their patients are lesbian, gay, or bisexual (LGB) and how many are transgender, and how many of their patients have an LGBT family member or friend involved in their care.

**Disparities in care to LGBT patients.** Respondents were asked whether they think LGB patients, in comparison with non-LGB patients, are more likely to experience discrimination when accessing health care at their institution. This question was also asked about transgender patients. Respondents were asked whether they had observed instances wherein a patient received inadequate, disrespectful, or abusive care due to being LGB. If so, they were asked to indicate which of each of these they had observed. These questions were also asked about transgender patients. Respondents were asked, based on their experience with patients or conversations with colleagues, how likely they think it is that LGB patients delay seeking health care due to fear of discrimination based on sexual orientation and how likely it is that transgender patients delay seeking health care due to this fear based on sexual identity.

**Discriminatory care to the family and friends of LGBT patients.** Respondents were asked whether they had observed instances of each of these types of discriminatory care to the spouse, partner, or health care surrogate of an LGBT patient: (1) having visiting hours limited; (2) being denied or having limited access to patient in the intensive care unit (ICU) or emergency department (ED); (3) having their treatment decisions disregarded or minimized; (4) being denied private time with the patient; (5) being treated disrespectfully; or (6) being treated abusively. They were asked whether they thought family members or friends are more likely to experience discrimination if they or the patient is LGBT.

**Professional and personal characteristics.** Professional characteristics included profession, years in professional practice, number of years they worked in palliative or hospice care, number of years at their current institution or agency, role at their institution (clinical, administration, and other), primary work setting, agency auspices (public/government, nonprofit secular, nonprofit religious, or for-profit), number of beds in the facility or typical agency caseload, state where

they work, and urbanicity where they work. Personal characteristics included gender identity, sexual orientation, age, religious affiliation, and religiosity or spirituality.

### **Statistical analysis**

Bivariate analyses using two-tailed tests for chi-square, *t* test, and analysis of variance using SPSS<sup>19</sup> were conducted to examine the associations between the professional and personal characteristics with the other study measures. Binomial logistic regression was used to obtain adjusted estimates of the relationship between professional and personal characteristics with inadequate care and with disrespectful care, for each of LGB and transgender patients. Final models were estimated by including all professional and personal characteristics that were significant in any one of these models, allowing for comparability of adjusted odds ratios across the four models.

## **Results**

### **Sample description**

Table 1 presents the professional and personal characteristics of the 865 respondents. Nurses were the largest group, with roughly equal proportions of physicians, chaplains, and social workers. On average, respondents had been in practice for ~18 years and in palliative and hospice care for >9 years. The majority had a clinical role, although many had an administrative role or other role. Home hospice and working on a palliative care team were the most common work settings. Over half of the respondents worked for a nonprofit secular agency or institution. Half of those working in an inpatient setting were in a hospital with >300 beds. Respondents were distributed similarly throughout all regions of the United States, with the exception of the Southwest, which had fewer respondents. Almost half worked in an urban area.

Respondents represented a range of age groups. The majority were Christian, with atheist or agnostic being the next largest group. The large majority reported being very or somewhat religious. There were 30.1% of respondents who reported that they were lesbian, gay, bisexual, or queer. The majority were female and <2% reported a gender other than female or male.

### **Clinical experience with LGBT patients**

Only 7.8% and 0.4% of respondents reported having 10 or more patients who were LGB or transgender, respectively, and 80.6% reported having no transgender patients or being unsure they had any such patients.

### **Disrespectful, inadequate, and abusive care to LGBT patients**

As indicated in Table 2, almost one-quarter of respondents had observed inadequate, disrespectful, or abusive care to LGB patients and 21.3% reported this for transgender patients. Although few reported abusive care to either LGB or transgender patients, inadequate care was not uncommon, and disrespectful care to LGB patients and to transgender patients was reported by 15.6% and 14.4%, respectively.

Table 3 shows the regression models for inadequate and disrespectful care to LGB patients and to transgender patients. Sexual orientation was the only characteristic signifi-

cant in all four of the models, with LGB respondents having 2.13–2.79 times higher odds of these outcomes than heterosexual respondents. All of the remaining variables were significant in only one of the four models and the professional and personal characteristics not included in the table were not significant in any of the models. Reports of abusive care were too rare to estimate a final model.

The majority of respondents reported that they thought LGB patients (53.6%) and transgender patients (64.3%) were more likely to experience discrimination than patients who were not LGB or transgender, respectively. Most respondents (89.7%) thought it was somewhat or very likely that LGB patients delayed care due to fear of discrimination, and an even higher percentage (94.8%) thought transgender patients delayed care due to such concerns.

### **Discriminatory actions observed toward the spouse, partner, or health care surrogate of LGBT patients**

Table 4 shows that 43% of respondents reported that they had directly observed a discriminatory action toward the spouse, partner, or legally designated health care surrogate of an LGBT patient. The most common types of discrimination were having their treatment decisions disregarded or minimized, and being treated disrespectfully. Other types of discrimination that were less frequent but not uncommon were being denied or having limited access to the LGBT patient in the ICU or ED, being denied private time with the patient, and having limited visiting hours.

Table 5 shows the final models for the four most common types of discriminatory actions toward the spouse, partner, or legally designated health care surrogate. Respondents who were LGB had 2.4–2.7 times higher odds than heterosexual respondents of reporting having observed any of the four most commonly reported discriminatory actions. Compared with social workers, chaplains had higher odds of reporting impaired access to the patient in the ICU or ED and lower odds of reporting that private time with the patient was denied. Respondents working in a state without a statute protecting LGBT persons from discrimination were more likely to report that spouse, partners, and surrogates have their treatment decisions disregarded or minimized, and were more likely to be denied private time with the patient. More years working in palliative and hospice care increased the odds of reporting that the treatment decisions of the spouse, partner, or health care surrogate were disregarded or minimized and of being denied private time with the patient. All of the remaining variables were significant in only one of the four models. The professional and personal characteristics not included in the final model were not significant in any of the models. Models could not be fit for the least common types of discriminatory actions due to rarity of the outcome.

There were 60.1% of respondents who reported that they thought that family members or friends of LGBT patients, as compared with those of heterosexual patients, were more likely to experience discrimination.

## **Discussion**

These findings provide strong evidence that LGBT patients and their families are more likely to receive discriminatory

TABLE 1. SAMPLE DESCRIPTION

<i>Characteristic</i>	<i>No.</i>	<i>Percent or mean (SD)</i>	
Personal characteristics			
Profession	Nurse (RN, NP, APN)	324	37.4
	Chaplain	172	19.9
	Physician	169	19.5
	Social worker	164	19.0
	Other	36	4.2
Years in practice	Professional practice	848	17.96 Years (11.77)
	Palliative or hospice care	848	9.41 Years (7.72)
	Current institution	856	7.83 Years (7.66)
Role <i>not mutually exclusive</i>	Clinical	775	71.2
	Administrative	292	26.8
	Other (education, ethics, research)	91	8.4
Primary work setting	Home hospice	241	27.8
	Palliative care team/service	239	27.5
	Inpatient (not PC or hospice)	132	15.2
	Outpatient	63	7.3
	Residential hospice	35	4.0
	Other	157	18.2
Agency/institution auspices	Nonprofit secular	448	51.9
	Nonprofit religious	157	18.2
	Public	133	15.4
Size of agency/institution	For profit	126	14.6
	<50 Beds	32	7.7
	50–150 Beds	57	13.8
	151–300 Beds	102	24.7
Region of workplace	More than 300 beds	222	53.8
	Northeast	217	25.5
	Midwest	199	23.4
	Southeast	181	21.3
	West and Pacific	176	20.7
Location of workplace	Southwest	77	9.1
	Urban	422	49.2
	Suburban	292	34.1
	Exurban or rural	143	16.7
Personal characteristics			
Age (years)	18–29	29	3.4
	30–39	164	19.1
	40–49	178	20.7
	50–59	268	31.2
	60–69	196	22.8
	70 or older	23	2.7
Religious affiliation	Protestant	279	32.8
	Catholic	133	15.6
	Other Christian	125	14.7
	Jewish	48	5.6
	Buddhist	30	3.5
	Hindu	8	0.9
	Muslim/Islam	3	0.4
	Native American traditions	1	0.1
	Atheist or agnostic	129	15.2
	Other	95	11.2
Religiosity/spirituality	Very religious or spiritual	388	45.4
	Somewhat religious or spiritual	342	40.0
	Very little or not at all religious or spiritual	124	14.5
Sexual orientation	Heterosexual	581	69.9
	Lesbian	100	12.0
	Gay	74	8.9
	Bisexual	52	6.3
	Queer	24	2.9
	Not listed	2	0.2
Gender identity	Female	643	75.6
	Male	195	22.9
	Nonbinary or gender nonconforming	10	1.2
	Trans male	1	0.1
	Trans female	1	0.1
	Not listed (trans masculine female)	1	0.1

APN, advanced practice nurse; NP, nurse practitioner; PC, palliative care; RN, registered nurse; SD, standard deviation.

TABLE 2. CARE TO LESBIAN, GAY, OR BISEXUAL AND TRANSGENDER PATIENTS

Care was not mutually exclusive	LGB patients		Transgender patients	
	No.	Percent	No.	Percent
Disrespectful	170	15.6	157	14.4
Inadequate	80	7.3	66	6.1
Abusive	17	1.6	19	1.7
Any of the above	210	23.7	184	21.3

LGB, lesbian, gay, or bisexual.

health care at some of the most vulnerable moments of their lives. Disrespectful care can negatively impact the trust patients have in their care providers and institutions, and lead to delaying or avoiding care, or not disclosing information that may be relevant. Partners and spouses may be treated disrespectfully, have their treatment decisions ignored or minimized, be denied or have limited access to the patient in the ICU or ED, and be denied private time with the patient.

LGB respondents were more likely to report discriminatory care than heterosexual respondents. It is unsurprising that LGB health care providers would be more aware of the quality of care LGBT patients and families receive. As members of a minority group accustomed to discrimination, they are more likely than their heterosexual colleagues to recognize discrimination against LGBT patients and families, from overt manifestations to more subtle nuances of disrespectful and neglectful behaviors.

**Implications for policy and practice**

The current political climate and actions by the Trump administration make it even harder to address the discrimination found in this research. Federal civil rights laws do not explicitly protect LGBT persons from discrimination in public accommodations, including health care. The Trump administration has argued before the U.S. Supreme Court that gender-based protections under Title VII of the Civil Rights Act of 1964 do not apply to claims of discrimination based on sexual orientation or gender identity.<sup>20</sup> In addition, the application of existing federal regulatory protections may be compromised by a “conscience rule” announced by the administration in May 2019 allowing health care professionals and entities that receive federal support to decline care that goes against their moral or spiritual beliefs.<sup>21</sup> The administration also proposed repealing protections under the Affordable Care Act that protect transgender patients from discrimination.<sup>22</sup> If these regulations are upheld after court challenges, it will be easier to discriminate against LGBT persons. Finally, the administration removed sexual orientation and gender identity questions from a national aging survey and did not add a transgender identity field to a national disability survey as was planned.<sup>23</sup>

Twenty states, primarily in the Northeast, West Coast, and upper Midwest, and the District of Columbia, have statutes with protections based on sexual orientation and gender identity.<sup>5</sup> We found that working in a state without a statute protecting LGBT persons, as compared with working in a state with such a statute, increased the odds of reporting discrimination toward partners, spouses, and surrogates. Having their treatment

TABLE 3. LOGISTIC REGRESSION MODELS ON INADEQUATE AND DISRESPECTFUL CARE DUE TO BEING LESBIAN, GAY, OR BISEXUAL OR TRANSGENDER

Professional and personal characteristics		Care was inadequate due to patient being <sup>a</sup>		Care was disrespectful due to patient being <sup>a</sup>					
		LGB		Transgender					
		OR	p	OR	p				
Primary work setting; Ref. cat.: Palliative care team or service	Inpatient (other than PC or hospice)	0.60	0.24	2.00	0.08	0.92	0.76	1.14	0.62
	Outpatient, community, or independent practice	1.50	0.29	<b>2.70</b>	<b>0.02</b>	1.24	0.47	1.06	0.85
	Home, residential, and inpatient hospice	1.16	0.67	1.20	0.65	1.07	0.80	0.62	0.07
	LTC, rehabilitation, and other	1.56	0.58	0.00	0.99	0.26	0.21	0.26	0.20
Agency/institution auspices; Ref. cat.: nonprofit secular	Public/government	1.07	0.85	1.43	0.34	<b>1.88</b>	<b>0.01</b>	1.31	0.30
	Nonprofit religious	0.94	0.87	1.18	0.65	1.07	0.80	1.06	0.83
	For profit	0.77	0.50	0.72	0.49	0.94	0.83	0.55	0.10
Type of area mostly work; Ref. cat.: urban	Suburban	0.95	0.85	0.96	0.89	0.83	0.40	<b>0.52</b>	<b>&lt;0.01</b>
	Exurban or rural	0.76	0.48	0.69	0.41	1.39	0.21	0.74	0.31
Gender identity; Ref. cat.: female	Male	1.16	0.63	1.22	0.52	1.14	0.54	1.11	0.64
	Nonbinary	1.45	0.65	1.78	0.49	2.43	0.16	<b>5.75</b>	<b>0.01</b>
Sexual orientation (Ref. Cat.: heterosexual)	LGB	<b>2.52</b>	<b>&lt;0.001</b>	<b>2.13</b>	<b>&lt;0.01</b>	<b>2.35</b>	<b>&lt;0.001</b>	<b>2.79</b>	<b>&lt;0.001</b>
No.		821		821		787		821	
Nagelkerke R <sup>2</sup>		0.05		0.07		0.08		0.14	
Model p-value		0.07		0.02		<0.001		<0.001	

<sup>a</sup>Significant ORs are in bold. LTC, long-term care; OR, odds ratio.

TABLE 4. DISCRIMINATORY ACTIONS OBSERVED TOWARD SPOUSE, PARTNER, OR LEGALLY DESIGNATED HEALTH CARE SURROGATE OF A LESBIAN, GAY, BISEXUAL, OR TRANSGENDER PATIENT

Type of discrimination not mutually exclusive	No.	Percent
Treatment decisions disregarded or minimized	163	15.0
Treated disrespectfully	156	14.3
Denied or having limited access to patient in ICU or ED	93	8.5
Denied private time with patient	80	7.3
Visiting hours limited	54	5.0
Other	39	3.6
Treated abusively	12	1.1
Have not observed the mentioned actions	621	57.0

ED, emergency department; ICU, intensive care unit.

decisions minimized or disregarded results in ignoring the advance care planning by the patient and having LGBT patients not receiving the end-of-life care they wanted and for which they had planned.<sup>24</sup> Enactment of the federal Equality Act, which passed the House of Representatives in May 2019,<sup>25</sup> and

state civil rights protections where they do not currently exist, are vital steps toward addressing discrimination by health care providers. Moreover, it will fall to future administrations and the federal agencies involved in the care of older adults, such as the Centers for Medicare and Medicaid, the Administration for Community Living, and the U.S. Justice Department, to protect the civil rights of LGBT patients. However, even without these federal protections, health care providers are required to follow the surrogate's treatment decisions, except when it is believed that the surrogate is making a poor decision or one that the patient would not want.

Staff training is necessary to improve the care of LGBT patients with serious illness.<sup>24</sup> Hospice and palliative care associations recognize the importance of promoting culturally sensitive and respectful care among diverse populations and communities.<sup>26,27</sup> Training is important to increase understanding of sexual orientation and gender identity, including the medical, psychosocial, legal, and spiritual issues of LGBT patients and families, and to respectfully identify patients and family members who are LGBT.<sup>6</sup> Strategies are needed to meet the unique concerns of LGBT patients and their families, and to report and respond to discriminatory acts. Training should also promote staff sensitivity, compassion, empathy, and comfort. SAGE, a national organization

TABLE 5. LOGISTIC REGRESSION MODELS ON DISCRIMINATORY TREATMENT OF SPOUSES, PARTNERS, AND HEALTH CARE SURROGATES OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER PATIENTS

		Type of discriminatory treatment <sup>a</sup>							
		Their treatment decisions were disregarded or minimized		They were treated disrespectfully		They were denied or had limited access to the patient in the ICU or ED		They were denied private time with patient	
Professional and personal characteristics		OR	p	OR	p	OR	p	OR	p
Profession; Ref. cat.: Social workers	Nurse (RN, NP, APN)	0.60	0.17	0.69	0.18	1.28	0.55	0.65	0.11
	Chaplain	0.75	0.53	0.53	0.09	<b>2.51</b>	<b>0.05</b>	<b>0.46</b>	<b>0.04</b>
	Physician	0.76	0.51	1.33	0.35	1.23	0.65	0.77	0.40
Years in palliative or hospice care		1.03	0.14	1.01	0.43	1.04	0.06	<b>1.05</b>	<b>&lt;0.01</b>
Years at current institution/agency		0.98	0.27	0.99	0.66	<b>0.90</b>	<b>&lt;0.001</b>	<b>0.94</b>	<b>0.001</b>
Primary work setting; Ref. cat.: Palliative care team or service	Inpatient (other than PC or hospice)	1.30	0.58	<b>2.36</b>	<b>0.02</b>	0.97	0.94	1.67	0.14
	Outpatient, community or independent practice	1.39	0.45	<b>1.98</b>	<b>0.04</b>	0.99	0.98	1.03	0.94
	Home, residential, and inpatient hospice	0.98	0.97	1.42	0.22	0.64	0.23	0.98	0.94
	LTC, rehabilitation, and other	1.62	0.57	0.44	0.45	0.94	0.94	1.35	0.68
Type of area mostly work; Ref. cat.: Urban	Suburban	0.64	0.18	1.13	0.62	0.63	0.15	0.90	0.67
	Exurban or rural	1.00	1.00	<b>2.23</b>	<b>&lt;0.01</b>	1.09	0.81	1.36	0.28
Works in state without statute protecting LGBT persons		<b>2.29</b>	<b>&lt;0.01</b>	1.24	0.30	1.22	0.47	<b>1.79</b>	<b>&lt;0.01</b>
Age; Ref. cat.: 18–39 years	40–49 Years	1.60	0.29	0.91	0.76	1.33	0.52	1.03	0.93
	50–59 Years	1.77	0.17	0.60	0.09	1.96	0.09	0.88	0.67
	60+ Years	1.22	0.69	0.44	0.02	1.73	0.22	0.67	0.24
Sexual orientation; Ref. cat.: heterosexual	LGB	<b>2.63</b>	<b>&lt;0.001</b>	<b>2.36</b>	<b>&lt;0.001</b>	<b>2.44</b>	<b>0.001</b>	<b>2.67</b>	<b>&lt;0.001</b>
No.		758		758		758		758	
Nagelkerke R <sup>2</sup>		0.02		0.10		0.13		0.11	
Model p-value		<0.001		<0.001		<0.001		<0.001	

<sup>a</sup>Significant ORs are in bold.  
LGBT, lesbian, gay, bisexual, and transgender.

serving LGBT older adults, provides a model for training staff to identify abuse of LGBT patients and treat them with respect and competence.<sup>28</sup> Manualized training should be developed and evaluated to ensure that staff at all hospice and palliative care programs are culturally competent in this area.<sup>29</sup>

In addition to training, programs should implement and enforce nondiscrimination policies that apply to all aspects of their organizations, including both staffing and services. Patients, families, and staff must be able to report discriminatory behaviors, and have their concerns listened to and effectively addressed. Institutional policies should promote LGBT-inclusive employment practices, engage in community outreach, and develop services that respond to community needs.<sup>29</sup>

### Strengths and limitations

The main study limitation is lack of a representative sample and the resulting selection bias. It is very likely that professionals with a strong interest in this topic are overrepresented in the sample. The percentage of lesbian, gay, bisexual, and queer respondents is almost 10 times greater than estimates of their percentage in the United States.<sup>30</sup> However, our finding that LGB respondents were more likely to report inadequate and disrespectful care to LGB and transgender patients and disrespectful treatment of their spouse, partner, and surrogate does not indicate that this finding is biased. It likely reflects greater sensitivity and recognition of incidents of substandard care. The lack of transgender persons in the sample is also a limitation.

Study strengths include a large sample drawn from all professions on the core palliative care team that is diverse in many important ways, including by discipline, geographic region, practice setting, urbanicity, religiosity/spirituality, age, and gender. The study includes a wide range of measures in multiple domains. Several of the measures distinguish between LGB and transgender persons, which is often not done in prior research.

### Future research

This study sought to understand the experiences of LGBT patients and families and the scope of disparities in care before recruiting patients and families into a research study at a very vulnerable time in their lives. Future studies should include LGBT patients and family members to hear directly about their experience with disparities in care using mixed methods. Those studies should include an adequate numbers of bisexual and transgender persons to have sufficient statistical power to describe their experience, and also in-depth interviews with health care providers to learn about their experiences with discriminatory care to LGBT patients and families.

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