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Project Respect: experiences of seriously ill LGBTQ+ patients and partners with their health care providers

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Abstract

Discrimination against lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons in health care creates barriers to serious illness care, including patients avoiding or delaying necessary care, providers disrespecting wishes of surrogates, and adverse outcomes for patients and families. A cross-sectional mixed-methods study using an online survey was used to determine the extent to which LGBTQ+ patients and spouses, partners, and widows experienced disrespectful or inadequate care due to sexual orientation or gender identity. A total of 290 LGBTQ+ patients and partners reported high levels of disrespectful and inadequate care, including 35.2% stating their provider was insensitive to them because of their identity; 30% reporting their provider was unaware of LGBTQ+ health needs; 23.1% feeling judged; 20.7% experiencing rudeness; 20.3% stating providers did not use their correct pronouns; and 19.7% reporting their treatment decisions were disregarded. Black and Hispanic patients were 2–4 times more likely than non-Hispanic White patients to report discrimination. This study demonstrated high levels of disrespectful and inadequate care towards patients and partners due to being LGBTQ+, which was especially problematic for Black and Hispanic patients and those living in politically conservative regions. Recommendations include federal and state civil rights laws to prohibit LGBTQ+ discrimination and institutional practices to address discrimination, including cultural sensitivity training for staff.

Key words: LGBTQ; LGBT; LBGTQ+; palliative care; serious illness care; discrimination; access to care.

Introduction

The lesbian, gay, bisexual, transgender, and queer (LGBTQ+) community is at a crossroads in the United States. During the past decade, the community has seen major advancements in the social, cultural, and legal landscape. These have included the legal recognition of same-sex marriages and expanded civil rights protections by the US Supreme Court,[1,2] expansion of state LGBTQ-based civil rights protections to 22 states and the District of Columbia,[3] greater support for a federal civil rights bill, and wider acceptance in the broader culture.[4] Unfortunately, the United States has recently witnessed greater backlash to these advances from conservative politicians, organized groups, and individuals, especially in Republican-led states, with increases in harassment, hate crimes, and discrimination.[4-6] The American Civil Liberties Union (ACLU) reports a growing trend in state anti-LGBTQ laws. During the 2023 legislative session, the organization tracked 496 anti-LGBTQ laws across the country; 84 bills became law in Republican-led states, with 26 laws addressing health care (as of September 7, 2023).[7] These bills include policies to restrict and deny access to gender-affirming care, primarily for trans youth, as well as efforts to censor discussions and reading materials about sexual orientation and gender identity in schools and libraries; drag performances have been banned, and adults who support LGBTQ+ youth have been labelled, chillingly, as "groomers."[8] Increasing political divides, societal stigma, hate-based violence, and anti-LGBTQ+ policies seek to further marginalize LGBTQ+ people without considering community concerns.[9-11]

Multilevel socioeconomic, cultural, and political determinants place LGBTQ+ individuals at higher risks for anxiety, depression, suicidality, substance abuse, homelessness, financial hardship, and social isolation across the lifespan.[11,12] In

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palliative and end-of-life care, LGBTQ+ patients with serious illness frequently encounter many discriminatory behaviors that lead to poor psychosocial and physical outcomes.[13,14] A recent systematic review analyzed the palliative and end-of-life needs, experiences, and preferences of LGBTQ+ patients with serious illness.[15] Needs included greater levels of social support, institutional safety, economic and legal supports, and advocacy efforts to decrease health barriers. Patient experiences were characterized by fears of discrimination, social isolation, and an undignified death. In addition, patients preferred including chosen family in health decision making, disclosure of sexual orientation and gender identity if the clinical environment was perceived as being safe, and strong desires to preserve individual autonomy.[15]

Just as LGBTQ+ communities reflect a range of identities, the inequities and experiences they confront are also diverse across cultures and settings.[16-21] For example, some transgender patients have reported preferences for foregoing medical care or aid-in-dying rather than face loss of functional independence and decisional autonomy, mostly due to fears of being mistreated or harmed by health care professionals.[22-25] When interviewed about the barriers and facilitators of advance-care planning, many LGBTQ+ patients have described concerns about whether end-of-life preferences and chosen decision-makers would be supported, as well as the desire to discuss health care decisions outside the clinical setting due to perceived lack of safety.[26] The chosen family members of LGBTQ+ patients—including spouses, partners, friends, and nonbiological surrogates and caregivers—also commonly experience exclusion and bias,[12,27-29] leading to adverse outcomes, such as greater psychological distress[30] and disenfranchised grief and bereavement.[30-32]

These concerns, fears, and worries have been validated. In the authors' previous study, 865 interprofessional hospice and palliative care providers were surveyed about their perspectives on LGBT patients' and families' hospice and palliative care experiences.[33-35] More than half of respondents (54%) thought that lesbian, gay and bisexual (LGB) patients were more likely to experience discrimination in their health system than non-LGB patients and 24% directly observed discriminatory care toward LGB patients. In addition, 64% of providers thought transgender patients were more likely to receive discriminatory care than non-transgender patients and 21% witnessed such behavior. Respondents also reported that treatment decisions of LGBT patients' spouses and partners were minimized or ignored (15%) and that the spouse, partner, or surrogate of LGBT patients were treated with disrespect (14%).[35]

There are limited available data on the lived experiences of LGBTQ+ patients in palliative and end-of-life care.[15,36-38] Such data are necessary to address disparities in serious illness care for these patients and inform evidence-based policy development. Building on the authors' past research,[35,39-42] this report presents an analysis of the experiences of LGBTQ+ patients with serious illness and their spouses, partners, and widows in their encounters with health care providers.

Data and methods

Study design

A cross-sectional study using mixed methods was conducted using an online survey. This study was approved by the Institutional Review Boards at Yeshiva University (IRB #1303817) and Fordham University (#1830).

Sample

Respondents were LGBTQ+ patients with a serious illness and the spouses, partners, and widows of LGBTQ+ patients with a serious illness. Caregivers were also invited, but only 2 responded and were excluded from the sample due to the very small number. They were recruited from organizations serving the LGBTQ+ community, eldercare organizations, health care organizations (including hospices and hospital-based palliative care programs), and medical centers in the United States. An announcement was posted on organizational websites, social media, newsletters, and virtual and physical bulletin boards of LGBTQ+, health care, and elder organizations with whom the researchers communicated. Word of mouth was also used.

Responses were checked to be sure they were entered by a respondent who met the eligibility criteria. Respondents with extensive missing information were also removed from the sample. Responses to open-ended questions were examined for consistency with the question; this did not result in removing any respondents. There was no monetary incentive for completing the survey, minimizing the possibility of ineligible respondents.

Measures

Respondents who were patients were asked whether they had experienced disrespectful or inadequate care due to being LGBTQ+. Those who had were asked whether they had experienced each of 11 types of disrespectful or inadequate care from a health care professional, which was described as a physician, nurse, social worker, or chaplain. They were also asked if they had experienced each of these types of care from support staff, which was described as a nursing aide or home health aide. They were then asked if their partner had experienced each of 5 types of discriminatory care. Respondents who were a spouse, partner, or widow were asked comparable questions about the patient and about their own experiences.

Sociodemographic characteristics that were measured included the following: gender, sexual orientation, age, race and ethnicity, state where they resided, illness, health care services they received, and settings where the patient was treated for their serious illness.

Data analysis plan

Univariate statistics were used to examine missing values and determine the need to combine response categories with small counts. Chi-square statistics were used to examine associations between sociodemographic characteristics and types of discriminatory care. Multivariable analyses were not possible given the small cell sizes for many of the sociodemographic variables, even after combining categories.

Results

Sample description

There were 290 respondents, including 173 patients (59.7%), 82 spouses/partners (28.3%), and 35 widows (12.1%). Table 1 presents the characteristics of the sample. Three-quarters of the sample were male or female and

Table 1. Sample characteristics.

Characteristic	*n*	%
Gender		
Female	115	40.5
Male	100	35.2
Transgender man	25	8.8
Gender nonbinary	24	8.5
Transgender woman	15	5.3
Not listed	5	1.8
Sexual orientation		
Lesbian	121	42.6
Gay	102	35.9
Queer	41	14.4
Bisexual	9	3.2
Heterosexual patient (spouse was LGBTQ+)	3	1.1
Not listed	8	2.8
Age		
18–29 y	51	19.2
30–39 y	57	21.5
40–49 y	34	12.8
50–59 y	37	14.0
60–69 y	52	19.6
70–79 y	30	11.3
80–89 y	4	1.5
Race/ethnicity (not mutually exclusive)		
Non-Hispanic White	209	72.1
Hispanic/Latino	73	25.2
Black	34	11.7
East Asian	19	6.6
South Asian	12	4.1
Native American or Alaskan Native	12	4.1
Pacific Islander	8	2.8
Middle Eastern or North African	7	2.4
Not listed	7	2.4
Region		
Northeast	101	39.6
West and Pacific	63	24.7
Southeast	41	16.1
Midwest	30	11.8
Southwest	20	7.8
Illness (not mutually exclusive)		
Cancer	80	27.6
Heart disease	41	14.1
Neurological disorder	40	13.8
Respiratory illness	35	12.1
HIV or AIDS	34	11.7
Cardiovascular disease	26	9.0
Kidney disease	26	9.0
COVID-19	21	7.2
Liver disease	14	4.8
Other	65	22.4
Treatment setting (not mutually exclusive)		
Outpatient clinic or doctor's office	179	61.7
Hospital inpatient	125	43.1
Rehabilitation facility	47	16.2
Palliative care specialist	44	15.2
Clergy or spiritual advisor	30	10.3
Home hospice	23	7.9
Nursing home	18	6.2
Non-home hospice	14	4.8

22.6% were transgender or gender nonbinary. There were 78.5% who identified as lesbian or gay, 14.4% who identified as queer, and only 3.2% ($n = 9$) who identified as bisexual. All age groups from 18 to 79 years were well represented in the sample, as were regions of the United States. The majority of the sample were non-Hispanic White (72.1%), with adequate representation of respondents who were Black (11.7%) or Hispanic (25.2%), and 30% who were bi- or multiracial (race/ethnicity categories are not mutually exclusive). The most common diagnoses reported were cancer, heart disease, neurological disorder, respiratory illness, and HIV/AIDS. The most common treatment settings were outpatient clinic or doctor's office, hospital inpatient, rehabilitation facility, palliative care specialist, and clergy or spiritual advisor.

Table 2. Discriminatory actions of health care providers and support staff due to patient being LGBTQ+.

	Health care provider		Support staff	
Discriminatory action	***n***	**%**	***n***	**%**
Discriminatory actions to patient				
Insensitive to me as an LGBTQ+ person	102	35.2	44	15.2
Was not aware of LGBTQ+ health needs	87	30.0	72	24.8
Made me feel judged for being LGBTQ+	67	23.1	41	14.1
Were rude to me	60	20.7	56	19.3
Didn't use my correct pronouns (he, she, or they)	59	20.3	49	16.9
Disregarded my treatment decisions	57	19.7	36	12.4
Imposed their religious beliefs on me	50	17.2	40	13.8
Denied or refused care to me	49	16.9	31	10.7
Used my birth name instead of my chosen name	46	15.9	41	14.1
Violated my privacy	39	13.4	39	13.4
Made fun of me	33	11.4	35	12.1
Discriminatory actions to partner	***n***		**%**	
They were denied access to you in intensive care or emergency room	36		12.4	
They felt they were treated badly	35		12.1	
Their decisions about your care were not followed	29		10.0	
Their visiting hours with you were limited	23		7.9	
They were denied private time with you	21		7.2	

Discriminatory care

The discriminatory actions of health care providers and support staff due to the patient being LGBTQ+ are reported in Table 2. Among types of inadequate care, patients reported that their providers were unaware of LGBTQ+ health needs (30%), disregarded their treatment decisions (19.7%), and denied or refused them care (16.9%). High levels of disrespectful care were reported, including providers who were insensitive to them for being LGBTQ+ (35.2%), feeling judged (23.1%), being treated rudely (20.7%), and having religious beliefs imposed on them (17.2%) by providers. Using incorrect pronouns and birth names was also common. Support staff were also frequently reported as providing inadequate and disrespectful care, at similar or slightly lower levels than reported for health care providers.

Partners reported that they were denied access to their loved one in intensive care or the emergency room (12.4%), being treated badly (12.1%), and that their health care decisions were not followed (10%).

Associations between sociodemographic characteristics and discriminatory care

Associations between sexual orientation and discriminatory care to the patient and the partner are shown in Table 3. The numbers of bisexual and queer respondents are small and should be interpreted with caution. Gay men were more

Table 3. Discriminatory actions of health care provider by sexual orientation due to patient being LGBTQ+.

Discriminatory action	Gay		Lesbian		Bisexual		Queer		*P* (chi-square)
	n	%	*n*	%	*n*	%	*n*	%	
To patient									
Insensitive to me as an LGBTQ+ person	39	38.2	35	28.9	6	66.7	17	41.5	.07
Were rude to me	17	16.7	27	22.3	2	22.2	12	29.3	.40
Made fun of me	19	18.6	7	5.8	2	22.2	5	12.2	.02
Imposed their religious beliefs on me	21	20.6	19	15.7	1	11.1	7	17.1	.75
Violated my privacy	14	13.7	9	7.4	2	22.2	12	29.3	.004
Denied or refused care to me	24	23.5	12	9.9	2	22.2	9	22.0	.04
Made me feel judged for being LGBTQ+	28	27.5	18	14.9	3	33.3	13	31.7	.05
Was not aware of LGBTQ+ health needs	25	24.5	35	28.9	4	44.4	18	43.9	.10
Disregarded my treatment decisions	23	22.5	18	14.9	2	22.2	13	31.7	.12
Didn't use my correct pronouns (he, she, or they)	17	16.7	13	10.7	5	55.6	19	46.3	<.001
Used my birth name instead of my chosen name	18	17.6	13	10.7	1	11.1	11	26.8	.09
To partner									
Their visiting hours with you were limited	10	9.8	11	9.1	0	0.0	1	2.4	.37
They were denied access to you in intensive care or emergency room	13	12.7	15	12.4	1	11.1	6	14.6	.98
Their decisions about your care were not followed	10	9.8	13	10.7	2	22.2	2	4.9	.43
They were denied private time with you	9	8.8	7	5.8	1	11.1	4	9.8	.75
They felt they were treated badly	12	11.8	13	10.7	3	33.3	6	14.6	.25

likely than lesbians to report being denied or refused care, to be made fun of, to have their privacy violated, and made to feel judged for being LGBTQ+. Queer respondents were more likely to report that their correct pronouns were not used. Sexual orientation was not associated with any of the discriminatory actions toward partners.

The relationships between gender and discriminatory care to the patient and partner were consistent with those seen for sexual orientation. Males were more likely than females and transgender/gender nonbinary persons to report that health care providers denied or refused them care, and that they made fun of them. None of the other discriminatory actions by health care providers, nor the discriminatory actions toward partners, were associated with gender. Transgender patients were more likely to have their birth name used instead of their chosen name.

Almost all of the discriminatory actions of health care providers differed by race/ethnicity (Table 4). Black and Hispanic patients were 2 to 4 times more likely than non-Hispanic White patients to report experiencing discrimination. Similar patterns were reported by their partners in relation to discriminatory actions that they experienced. For most of the discriminatory actions toward the patient and toward the partner, non-Black Hispanic participants reported the same or greater likelihood of these experiences as compared with Black participants.

Six of the discriminatory actions of health care providers toward the patient and all of the discriminatory actions to the partner differed by region, as shown in Table 5. Patients in the Northeast, as compared with other regions in the United States, were least likely to report receiving insensitive care due to being LGBTQ+, having a health care provider who was not aware of LGBTQ+ health needs, having religious beliefs imposed on them, having their privacy violated, and having a health care provider who did not use their correct pronouns and who used their birth name instead of their chosen name. Patients in the Southwest and Southeast typically reported much higher rates for each of these discriminatory actions, although those in the Midwest had rates that were similar to those in the Southwest and Southeast for some of these discriminatory actions. Region was also associated with discriminatory actions toward the partner. Those residing in the Northeast were least likely to report each of the 5 discriminatory actions.

Discussion

How do health care providers of serious illness care reflect sociocultural trends? This study presents some of the first data on the extent to which LGBTQ+ patients and partners experience problematic and discriminatory care for serious illness. These findings, in combination the authors' previous study on the perspectives of hospice and palliative care providers,[33-35] reveal high levels of concerning and ethically unacceptable care. Might the health care experiences of LGBTQ+ patients and their partners reflect societal upticks in harassment, discrimination, and hate crimes against this community?

Discriminatory care

In their prior study of the perceptions and observations of hospice and palliative care providers, the authors differentiated between health care that might be regarded as disrespectful or inadequate.[35] While disrespectful care might be viewed as less serious than care that is inadequate or abusive, such care can negatively impact the trust that patients have in their care providers and institutions, and lead to delaying or avoiding care, or not disclosing information (eg, sexual orientation, gender identity) that may be relevant to the provision of care. Providers who are disrespectful to patients because they are LGBTQ+ may be more likely than those who are respectful to deliver inadequate care.

Differences between gay men and lesbians

Gay men reported higher rates of discriminatory care than lesbians. For example, they were 3.2 times more likely to report being made fun of and 2.4 times more likely to report being denied or refused care than lesbians. This is consistent with a 2020 study that found higher levels of negative attitudes toward gay men compared with lesbians.[43]

Table 4. Discriminatory actions of health care provider by race due to patient being LGBTQ+.

	Non-Hispanic White		Black only or multiracial, including Hispanic		Non-Black Hispanic		
Discriminatory action	***n***	**%**	***n***	**%**	***n***	**%**	***P* (chi-square)**
To patient							
Insensitive to me as an LGBTQ+ person	42	25.0	16	47.1	40	70.2	<.001
Were rude to me	28	16.7	11	32.4	20	35.1	.006
Made fun of me	3	1.8	6	17.6	23	40.4	<.001
Imposed their religious beliefs on me	19	11.3	9	26.5	22	38.6	<.001
Violated my privacy	11	6.5	8	23.5	19	33.3	<.001
Denied or refused care to me	18	10.7	10	29.4	21	36.8	<.001
Made me feel judged for being LGBTQ+	28	16.7	13	38.2	24	42.1	<.001
Was not aware of LGBTQ+ health needs	50	29.8	14	41.2	21	36.8	.332
Disregarded my treatment decisions	19	11.3	13	38.2	23	40.4	<.001
Didn't use my correct pronouns (he, she, or they)	21	12.5	13	38.2	24	42.1	<.001
Used my birth name instead of my chosen name	14	8.3	10	29.4	21	36.8	<.001
To partner							
Their visiting hours with you were limited	9	5.4	2	5.9	12	21.1	.001
They were denied access to you in intensive care or emergency room	10	6.0	7	20.6	19	33.3	<.001
Their decisions about your care were not followed	8	4.8	8	23.5	13	22.8	<.001
They were denied private time with you	6	3.6	6	17.6	9	15.8	.001[a]
They felt they were treated badly	16	9.5	5	14.7	13	22.8	.036

[a]Chi-square is not valid due to 33.3% of cells having an expected count <5.

Table 5. Discriminatory actions of health care provider by region due to patient being LGBTQ+.

Discriminatory action	Northeast		Midwest		Southeast		Southwest		West and Pacific		*P* (chi-square)
	n	%	*n*	%	*n*	%	*n*	%	*n*	%	
To patient											
Insensitive to me as an LGBTQ+ person	22	21.8	14	46.7	25	61.0	11	55.0	25	39.7	<.001
Were rude to me	20	19.8	7	23.3	11	26.8	7	35.0	12	19.0	.54
Made fun of me	6	5.9	5	16.7	8	19.5	2	10.0	8	12.7	.16
Imposed their religious beliefs on me	10	9.9	7	23.3	10	24.4	8	40.0	13	20.6	.01
Violated my privacy	8	7.9	4	13.3	11	26.8	1	5.0	12	19.0	.02
Denied or refused care to me	12	11.9	5	16.7	10	24.4	6	30.0	14	22.2	.18
Made me feel judged for being LGBTQ+	20	19.8	6	20.0	14	34.1	7	35.0	19	30.2	.25
Was not aware of LGBTQ+ health needs	21	20.8	11	36.7	21	51.2	9	45.0	20	31.7	.006
Disregarded my treatment decisions	15	14.9	6	20.0	13	31.7	5	25.0	15	23.8	.23
Didn't use my correct pronouns (he, she, or they)	13	12.9	8	26.7	15	36.6	5	25.0	16	25.4	.03
Used my birth name instead of my chosen name	7	6.9	7	23.3	11	26.8	4	20.0	12	19.0	.02
To partner											
Their visiting hours with you were limited	3	3.0	0	0.0	8	19.5	3	15.0	8	12.7	.004
They were denied access to you in intensive care or emergency room	3	3.0	4	13.3	10	24.4	5	25.0	11	17.5	.002
Their decisions about your care were not followed	3	3.0	6	20.0	9	22.0	2	10.0	8	12.7	.006
They were denied private time with you	2	2.0	6	20.0	8	19.5	1	5.0	3	4.8	<.001
They felt they were treated badly	7	6.9	4	13.3	11	26.8	3	15.0	9	14.3	.04

Regional differences

It has been suggested that life in the United States reflects 2 very different sociocultural political perspectives.[44] The data were analyzed by region, which is often a proxy for such ideology. For example, the Northeast and West Coast's more liberal outlook mirrors the states that have passed civil rights laws that protect the LGBTQ community. Only 2 states in the more conservative Southeast and Southwest (New Mexico and Virginia) have civil rights laws protecting LGBTQ people.[3] Provider behaviors may reflect such regional distinctions.

Patients and partners receiving care in the Northeast were much less likely to report discriminatory care than those living in the Southeast or Southwest on most all measures of inadequate or disrespectful care. While practice and policy interventions, such as staff training, institutional nondiscrimination policies, and federal and state civil rights laws, are recommended to address such regional deficiencies, they might be less likely to occur in or be supported by the regions with the highest levels of discriminatory care. Moreover, 9 mostly southern states have passed laws to allow for religious objections to providing care to LGBTQ patients.[45]

Transgender concerns

The transgender community has been particularly targeted in Republican-led states in recent years. While many policies focus on access to gender-affirming care for trans youth, or censorship of books or discussions on gender identity and sexual orientation in libraries and schools, the stigmatizing effect has been on all age groups. Hate crimes and violence have been rising, particularly towards transgender individuals and the drag community,[4,5] and anti-transgender rhetoric has increasingly become a focus for political discourse and policy action.

Transgender patients desire respect for their identity—that their chosen name be used rather than their birth name and that they be regarded by their correct pronouns. A plurality of transgender patients reported that their provider failed to use their correct pronouns. Although misgendering might stem from a lack of provider awareness about transgender health needs, this behavior might also result from a desire to belittle or disrespect these individuals. These concerns were more likely to be raised by LGBTQ+ patients living in politically conservative regions.

Impact of race/ethnicity

Poorer health outcomes and related disparities based on race and ethnicity have been well documented over decades.[46-48] Our findings are consistent with the health disparities literature—Black and non-White Hispanics reported much higher rates of discriminatory actions for most all provider behaviors. These provider behaviors may increase distrust among LGBTQ+ patients of color, and may lead to patients delaying or avoiding necessary care, as well as receiving lower quality care. Efforts to promote LGBTQ+-inclusive health care should also address the impact of disparities and provider bias based on race and ethnicity.

Nondiscrimination policy

While institutional nondiscrimination policies may not directly enhance staff behavior towards patients, they make clear that all patients are to be treated with equity and care,

regardless of their backgrounds and identities. While these statements are beneficial for all programs providing serious illness care, they are particularly important in states that fail to provide civil rights protections for the LGBTQ+ community. Such statements create important expectations to patients and communities that organizations respect their identities and to staff that management will not tolerate discriminatory behavior. Programs should review their institutional nondiscrimination policies to ensure that they protect patients and employees from discrimination based on sexual orientation and gender identity and expression. Model policies have been developed as guidance for employers.[49] In addition to nondiscrimination statements, providers should create guidelines to identify, report, and respond to complaints of discriminatory care.[50]

Our findings provide strong evidence that LGBTQ+ patients and partners face a greater likelihood of discriminatory care across all regions. They demonstrate the need for national civil rights laws protecting LGBTQ+ people, such as the Federal Equality Act,[51] which would broaden federal civil rights laws to include sexual orientation and gender identity, as well as civil rights laws in the 28 states that lack such inclusion.

Staff training

Both professional and support staff require training to ensure safe and respectful care for LGBTQ+ patients and their partners, families, and friends. Staff frequently require guidance to create environments perceived as welcoming and intake practices that inquire about sexual orientation, gender identity, and important relationships in a nonjudgmental and routine manner.[50] Our findings point to the importance of staff training—many providers were reported to be insensitive to LGBTQ+ patients and not aware of their health needs. Training should incorporate the range of medical, psychosocial, spiritual, and legal concerns of the LGBTQ+ community, including awareness of the special needs for advance-care planning. Due to the current stigmatization of the transgender community, training should promote staff comfort in caring for people who identify as trans. SAGE (Advocacy & Services for LGBTQ+ Elders), a national organization supporting LGBTQ+ older adults, offers model guides to promote inclusive and welcoming services.[52] All training efforts should be evaluated to determine which strategies positively influence provider behavior and patient care.

Role of support staff

Support staff, including aides and certified nurse assistants, provide patients with vital day-to-day personal care. While respondents reported somewhat lower levels of discriminatory care by support staff than by professional providers, almost one-quarter noted their lack of awareness of LGBTQ+ health needs. Preventive and remedial strategies, including nondiscrimination policies and cultural sensitivity training, should be considered. As there is often high turnover among support staff, learning needs to be assessed and training delivered periodically.

Strengths and limitations

This is one of few studies of LGBTQ+ patients and partners about their experiences with serious illness care.[15] Respondents represented a relatively large and diverse sample recruited from a wide range of internet sources, organizations, and social media. Despite these strengths, there are important limitations. Access to recruitment sources required internet connectivity and access to digital devices, which may impact participation by lower income communities, homeless persons, those living in rural areas, and older adults. The study did not recruit older adults residing at long-term-care facilities, where concerns about discrimination are noteworthy.[41,53,54] Inadequate statistical power to perform multivariable analyses limited our ability to examine differences among subgroups. Finally, the authors acknowledge that many of the concerns about serious illness care reported by our LGBTQ+ sample are shared among patients generally; it might have been useful to additionally include a comparison group of patients with which to measure our LGBTQ+ sample.

Future research

This study sought to understand the experiences of seriously ill LGBTQ+ patients and partners with health care providers. Future studies should examine the experiences of residents living in long-term-care facilities and their partners, in-depth patient experiences in parts of the country with less inclusive care, and including other family and friends closely involved in caregiving. Research should also examine differences in care by the degree to which patients have disclosed their sexual orientation and gender identity to their health care providers. In addition, in-depth evaluations are needed of practice and policy strategies, especially for staff training, that might prevent or ameliorate discriminatory care.

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Supplementary material

Supplementary material is available at *Health Affairs Scholar* online.

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Conflicts of interest

Please see ICMJE form(s) for author conflicts of interest. These have been provided as supplementary materials.

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