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Disrespectful and inadequate palliative care to lesbian, gay, and bisexual patients

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Abstract

Objectives. The study aims to describe inadequate, disrespectful, and abusive palliative and hospice care received by lesbian, gay, and bisexual (LGB) patients and their spouses/partners due to their sexual orientation or gender identity.

Methods. A national sample of 865 healthcare professionals recruited from palliative and hospice care professional organizations completed an online survey. Respondents were asked to describe their observations of inadequate, disrespectful, or abusive care to LGB patients and their spouses/partners.

Results. There were 15.6% who reported observing disrespectful care to LGB patients, 7.3% observed inadequate care, and 1.6% observed abusive care; 43% reported discriminatory care toward the spouses/partners. Disrespectful care to LGB patients included insensitive and judgmental attitudes and behaviors, gossip and ridicule, and disrespect of the spouse/partner. Inadequate care included denial of care; care that was delayed incomplete, or rushed; dismissive or antagonistic treatment; privacy and confidentiality violations; and dismissive treatment of the spouse/partner.

Significance of results. These findings provide evidence of discrimination faced by LGB patients and partners while receiving care for serious illness. Hospice and palliative care programs should promote respectful, inclusive, and affirming care for the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community, including policies and practices that are welcoming and supportive to both employees and patients. Staff at all levels should be trained to create safe and respectful environments for LGBTQ patients and their families.

Introduction

The lesbian, gay, bisexual, and transgender (LGBT) community has long faced stigma, discrimination, criminalization, violence, and disenfranchised grief (Choi and Meyer 2016). Older adults who came of age during the 1950s and early 1960s faced criminalization through so-called sodomy laws, widespread discrimination in employment and other areas of society, involuntary psychiatric treatment, and anti-LGBT violence. As a result, many remained closeted throughout their lives – stigma throughout their life span impacts the worldview of older LGBT adults. The baby boomer generation who grew up in the late 1960s and 1970s, and witnessed the Black, women's, and gay civil rights movements, will likely have different expectations about how they should be regarded and treated by all sectors of society.

Although LGBT patients hope to receive respectful healthcare and related services, free from societal stigma, discrimination, and abuse, the lived experience of many suggests challenges. This is a precarious time for LGBT individuals. Despite two decades of immense cultural change improving the lives of the community – including U.S. Supreme Court decisions enshrining marriage equality (Obergefell v. Hodges 2015) and wider application of civil rights laws in the employment sphere (Bostock v. Clayton County 2020) – the US is backsliding to less supportive times. Annual polling of the LGBT community finds diminishing levels of acceptance and increasing reports of discrimination and hate crimes, especially among people or color, and transgender and nonbinary people (GLAAD 2022). Conservative leaning politicians have led to states implementing policies to investigate parents who support their trans children, "Don't Say Gay" educational policies, moves to ban books from libraries and anti-transgender legislation. They have enacted policies that explicitly target LGBT youth, especially trans youth, and attack their adult supporters as groomers who are indoctrinating youth. These policies remind LGBT people of all ages, and especially older adults, of the urge to hide their identities (Brammer 2022; Ghorayshi 2022; Goldstein 2022).

Limited research from the US and UK provide evidence that LGBT patients and their partners experience relatively high levels of discrimination in hospice and palliative care and have special needs in receiving care. LGBT individuals who faced histories of discrimination in healthcare or inadequate care may be reluctant to disclose their sexual orientation or gender identity, fearing how they will be received by providers (AARP 2018; SAGE 2014; Stein and Bonuck 2001). Researchers from the UK interviewed 40 LGBT persons facing advanced illness, finding they faced societal stressors, increased isolation, family estrangement, and homophobia or transphobia and affected whether they disclosed their identity to healthcare providers (Bristowe et al. 2018). LGBT individuals worry about abuse and neglect by staff at all levels, especially health aides, and not receiving equal, appropriate, or safe treatment (Stein et al. 2010). Nursing home care is particularly troubling, with reports of high levels of mistreatment, harassment, and denial of care by long-term care staff (National Senior Citizens Law Center, National Gay and Lesbian Task Force, Services & Advocacy for GLBT Elders (SAGE), Lambda Legal, National Center for Lesbian Rights and National Center for Transgender Equality 2015).

In 2020, the authors reported findings from their survey of hospice and palliative care nurses, physicians, social workers, and chaplains on their perceptions and observations of discriminatory care affecting LGBT patients (Stein et al. 2020). Among 865 respondents, 53.6% thought that LGB patients were more likely non-LGB patients to experience discrimination at their institutions and 23.7% observed discriminatory care, with even higher percentages reporting discrimination toward transgender patients compared with non-trans patients. Spouses and partners experienced similar levels of discrimination – respondents observed partners having their treatment decisions ignored or minimized, being denied or having limited access to the patient, or being denied private time (Stein et al. 2020).

This report presents a qualitative analysis of the open-ended responses of hospice and palliative care nurses, physicians, social workers, and chaplains regarding inadequate, disrespectful, and abusive care received by LGB patients, as well as their spouses, partners, and healthcare surrogates, due to their sexual orientation or gender identity.

Methods

Study design

A cross-sectional study using mixed methods was conducted. Data were collected using an online survey. This study was approved by Institutional Review Boards at Albert Einstein College of Medicine/Yeshiva University (IRB #2018-8750) and Fordham University (#1057).

Sample

Respondents were recruited using a volunteer sampling method. The study population was seven professional organizations with membership from nursing, medicine, social work, and chaplaincy. The organizations include American Academy of Hospice and Palliative Medicine, Association of Professional Chaplains, HealthCare Chaplaincy Network, Center to Advance Palliative Care, Hospice and Palliative Nurses Association (HPNA), and Social Work Hospice and Palliative Care Network. Potential respondents were invited by an email to the membership and/or an announcement posted on the organization website or newsletter. An invitation was posted on the SW-PALL-EOL listserv for social workers. The National Coalition for Hospice and Palliative Care supported this study and promoted it among its organizational members. All palliative care team professionals and administrators of hospice and palliative care services were eligible to participate.

Measures

Respondents were asked whether or not they had observed instances where a patient has received inadequate, disrespectful, or abusive care due to being lesbian, gay, or bisexual. Those who responded yes were asked an open-ended question to describe what they observed in the instances where the patient received inadequate, disrespectful, or abusive care due to being lesbian, gay, or bisexual.

Data analysis

A grounded theory approach with constant comparison analysis was used to code the data. The first author read through all the responses and then coded the responses using in vivo coding. The researchers then jointly reviewed the first-level codes for approximately one-third of the respondents to eliminate redundancy and to achieve consensus on assigning the codes to the text. They then worked together to combine the first-level codes into higher level categories and then combined these into the final categories to describe the different types of disrespectful, inadequate, and abusive care.

Results

Sample description

There were 865 respondents, of whom nurses comprised 37.4% of the sample, with roughly equal proportions of physicians, chaplains, and social workers, at about 20% each (Stein et al. 2020). Respondents were experienced professionals, with a mean of 18 years (SD = 11.77) in practice and over 9 years (SD = 7.72) in palliative and hospice care. The most common work settings were home hospice (27.8%) and hospital-based palliative care team (27.5%). Almost half worked in an urban area. Respondents were distributed similarly throughout all regions of the US, except for the Southwest, which had fewer respondents. Respondents represented a range of age groups. The majority (63.1%) were Protestant, Catholic, or other Christian denomination, and most (85.4%) reported being very or somewhat religious. The majority (75.6%) were female, most of the other respondents were male (22.9%), and the remaining 1.5% reported a gender other than female or male. There were 30.1% of respondents who identified as lesbian, gay, bisexual, or queer.

Reported prevalence of disrespectful, inadequate, and abusive care to LGBT patients

There were 23% who reported having observed discriminatory care toward lesbian, gay, and bisexual (LGB) patients in their institution. This included 15.6% who observed disrespectful care, 7.3% who observed inadequate care, and 1.6% who observed abusive care toward an LGB patient. There were 43% who observed discriminatory care toward the spouse, partner, or healthcare surrogate of an LGBT patient.

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Responses are presented verbatim without edits, except for obvious typographical errors in spelling. When context is necessary for a phrase or sentence taken from a longer quote, it is provided in brackets.

Disrespectful care

Disrespectful care to LGB patients included a wide range of verbal and nonverbal expressions. Each of these types of disrespectful care are described with the data reported by study respondents that support them.

Insensitive and judgmental attitudes and behaviors

Respondents reported that staff at their institution made comments to colleagues, and sometimes to patients, indicating that their sexual orientation was not normal or was immoral.

> Patients are labeled as immoral and therefore "deserve" being ill.
>
> Staff thinking people are gross for being homosexual.
>
> Nurse asked lesbian pt and her wife who were surrounded by female friends if any REAL family would be visiting.
>
> Negative assumptions made about promiscuity & drug misuse.

Gossip and ridicule

There were numerous reports of staff gossiping about LGB patients and ridiculing their sexual orientation.

> Jokes made by the physician where the punchline is the pt's lesbian relationship.
>
> Staff making homophobic comments within earshot of patients.
>
> When I was working in an ER, a man had been attacked due to his sexual orientation. The physician … announced to the room loudly that he had poor rectal tone and then rolled his eyes and said "obviously."
>
> Name calling behind their back.
>
> Use of slang or derogatory terms.

Disrespect of spouse/partner

There were also many reports of disrespectful attitudes and behaviors toward the spouse or partner of an LGB patient. These include not acknowledging the spouse or partner as the significant other:

> Often the notes list a "friend" who is more properly a spouse or partner.
>
> Snidely referring to "friend."
>
> No respect for calling a married same sex couple as they chose to be called.
>
> Assuming that same sex partner is friend or sibling.
>
> I have observed nurses and nursing aides roll their eyes when they are informed the patient's same-sex partner is the healthcare proxy.

There were reports of the spouse or partner not being allowed to visit the patient.

> Patient's significant other being blocked by family to visit & staff not advocating for visits, especially at end of life.
>
> The clinical caregiver did not agree with the lifestyle and was not supportive of patient or her partner. Tried to block visitation.

Behavior accepted when exhibited by heterosexual couples was viewed as offensive for same-sex couples.

> End-of-life patients asked not to show public affection.
>
> Rolling eyes when couples held hands or show affection.

Inadequate care to LGB patients

There were many ways that care was inadequate for LGB patients. Respondents reported denial of care, delayed care, and avoidance of patients.

> The nurse refused to provide care because he was a gay male.
>
> Nurses avoiding contact with the patient.
>
> Lesbian pt receives delayed pain medication.

Incomplete, rushed, or dismissive treatment

Some staff did not conduct complete examinations or assessments due to their discomfort with LGB patients.

> Avoidance of discussion and a thorough examination due to discomfort by staff.
>
> Avoid taking a sexual history.
>
> Providers not asking full medical history questions as relate to sexuality/sexual practices to ascertain risk.
>
> Abbreviated care interactions, asking and doing the minimal care, not be fully present during care.

This behavior was sometimes attributed to the discomfort of staff.

> Avoidance of discussion and a thorough examination due to discomfort by staff.
>
> Staff did not feel comfortable touching a gay man fearing he may have AIDS.

The religious beliefs of staff were cited as a reason for refusing or providing minimal care to LGB patients.

> "Obvious" GL pts tend to receive minimal care from religious "Christian" RNs and CNAs who are uncomfortable with "those" pts.
>
> CNA told the pt they didn't believe in the pt's lifestyle, but that they would pray for them. She also told the pt she prayed about taking care of them because she was having a hard time with it.
>
> Staff trading off treatment due to "religious reasons."

LGB patients had their health concerns and symptoms minimized or ignored by staff, sometimes stating that symptoms are caused by their sexual orientation.

> Dismissive behavior by healthcare staff.
>
> When a patient seeks medical care, their symptoms or concerns are sometimes downplayed as being related to their sexual orientation.

Inadequate care sometimes led to LGB patients not sharing information with healthcare providers.

> Many LGBT people are selective about sharing information openly and unfortunately many people of all types who, like, overreact and are unaccepting of differences.

There were reports of care providers antagonizing patients.

> Micro-aggressions due to a heteronormative approach to care.
>
> Night shift nurses picking on him [gay patient], laughing when they made him angry.
>
> Nurse belittled the patient and his partner.
>
> Passive-aggressive behavior toward patient or family.

Privacy and confidentiality violations

The privacy and confidentiality of LGB patients was violated, with gratuitous sharing of the patient's sexual orientation with staff who had no need of this information.

> Highlighting sexual orientation in conversation with other staff.

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Sharing of information with other staff people not directly involved in the care.

People being outed without their consent.

Discussion of HIV+ status without the consent of the patient.

Dismissive treatment of spouse/partner

There were numerous reports of the spouse or partner being ignored and excluded from discussions about treatment and decision making.

> Not including partner in family meetings or decision making.
>
> Dismissive of same sex partner's concerns when responsive to them for a straight couple.
>
> Disrespectful in downplaying relationship of partner as decision-maker.
>
> Failure to address and include pt's same-sex partner in conversation.
>
> Partner not receiving correct information about advance directives, so that after death, partner could not cremate his body.
>
> I have witnessed partners of LGBTQ+ individuals be questioned by the primary team as to their status. For example, recently a nurse wouldn't share information with a pt's husband because she "didn't know that was legal in our state."

There were reports of staff incorrectly viewing the biological family as the appropriate or legal decision makers, despite oral or written directives to the contrary.

> Nurse prioritized mother as the decision maker against patient's wishes.
>
> Waiting for blood relations to discuss medical decisions.
>
> Estranged family members were compulsively brought in at the end of life for key medical decision making.

Abusive care

While there were reports of inadequate care that might have crossed the line into abusive care, we chose to apply this label very sparingly to care that was clearly abuse. These included

> Letting soiled diapers stay on too long.
>
> Lesbian pt ...receives delayed pain medication.
>
> Patient was gay and… bedbound and the staff was not coming in to assist in cleaning him. …he was covered in his feces, his urinal was full and his brief was soaking as well. …he attempted multiple times to call staff to come assist and they would ignore his requests.

Discussion

These findings, in combination with the quantitative data (Stein et al. 2020), evince concerning patterns of discrimination faced by LGB patients and partners while receiving care for serious illness. Hospice and palliative care professionals reported over 150 examples of care that are categorized as being disrespectful, inappropriate, or abusive due to the patient's or partner's sexual orientation or gender identity. Palliative care providers are not immune from recent upticks in discrimination against LGB individuals and their families, which requires redress at the level of individual practitioners, as well as institutional and public policy.

Disrespectful care

Although disrespectful care may be perceived as less serious than care that is inappropriate or abusive, it has serious consequences for patient care. Disrespectful care is serious because the words, facial expressions, and body language that transmit judgment, disapproval, and rejection are dehumanizing and hurtful to patients and their families and friends. Providers who have and communicate these attitudes and beliefs may also provide inadequate care to LGB people. They are likely offensive to LGB patients and their families and result in distrust of providers and the healthcare system. This leads to avoiding care or not sharing information with healthcare providers (AARP 2018; SAGE 2014; Stein and Bonuck 2001) which may cause poor outcomes for these patients.

The origins of disrespectful care – such as insensitive and judgmental attitudes and behaviors, gossip, and ridicule – may be due to religious and cultural beliefs, or dislike of the community. They may also be the result of inadequate professional training about treating LGB patients, including their medical and psychosocial issues. For example, oncology healthcare providers often lack knowledge about treating LGBT patients and require more education about healthcare for this population (Banerjee et al. 2018; Maingi et al. 2018, 2015). In addition, family caregivers are vital components of successful hospice and palliative care. Disrespect for spouses and partners – such as failing to acknowledge them, limiting hospital visitation, or asking couples to avoid expressions of affection and intimacy – may lead to distrust of healthcare providers and institutions.

Inadequate care

Inadequate care is particularly serious and may lead to legal liability due to negligence or violations of civil rights or Health Insurance Portability and Accountability Act laws. Such care includes rushed, denied, or delayed care; avoiding patients or their families; inappropriately transferring or dismissing patients; and violations of privacy and confidentiality standards. Dismissing spouses and partners as decision-makers, or preferring biological family over partners, is stressful to patients and partners, frequently counters expressed patient wishes, and may result in undesired care. As with disrespectful care, inadequate care may stem from provider discomfort of or lack of knowledge about the LGB community, or from religious or cultural beliefs.

Implications for policy and practice

Hospice and palliative care programs should promote respectful, inclusive, and affirming care for the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community. They should assess their institutional policies and practices to ascertain whether they are welcoming and supportive to both their employees and their patients (Pratt-Chapman et al. 2023). Four components of this assessment include the institutional nondiscrimination policy, employment policies, intake practices, and community outreach and marketing; these have been described as the four "planks" of LGBTQ-inclusive care (Acquaviva 2017).

Nondiscrimination policy

Institutional policies should clearly protect patients and employees from discrimination based on sexual orientation or gender identity and expression. This comports with the current state civil

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rights laws of 22 states, primarily in the Northeast, West Coast, and Midwest, and the District of Columbia (Movement Advancement Project, SAGE, and Center for American Progress 2022). The U.S. Supreme Court expanded the definition of gender in employment cases brought under Title VII of the Civil Rights Act of 1964 to include sexual orientation and gender identity, while the federal Department of Health and Human Services announced requirements for nondiscriminatory services in its programs, including services for the LGBT community (U.S. Department of Health & Human Services 2021). Organizational policy should reflect all legal requirements; they should include strategies to identify, report, and respond to discriminatory care.

Furthermore, organizations that wish to be inclusive and supportive should display the same respect for their LGBT employees. LGBT providers of palliative care have reported high levels of discrimination based on sexual orientation and gender identity (O'Mahony et al. 2020). Nondiscrimination policies should apply to all aspects of employment including hiring, compensation and benefits, and organizational culture.

Training

Staff at all levels should be trained to create safe and respectful environments for all LGBTQ patients and their families (Banerjee et al. 2018; Maingi et al. 2014). This includes intake staff who are welcoming to LGB patients and intake practices that routinely inquire about sexual orientation and gender identity, preferred names and pronouns, and who patients regard as their immediate family (Acquaviva 2017). Staff should be educated about the full service needs of their LGBTQ patients, including medical and psychosocial care sensitive to their needs, and legal considerations around advance care planning (Bristowe et al. 2018).

Outreach and marketing

Hospice and palliative care programs should use their public websites, marketing materials, and community outreach to visibly and explicitly affirm nondiscriminatory policies and care that are respectful and affirming of the LGBTQ community (Acquaviva 2017). Outreach presents an opportunity to engage the LGBTQ community for health education and marketing, and to obtain community input to enhance culturally competent care (Bristowe et al. 2018).

Strengths and limitations

There was selection bias in the sample due to the nonprobability sampling plan. Lesbian, gay, bisexual, and queer respondents were represented at almost 10 times their estimated proportion in the US (Gates 2011). This may have been an advantage for this study, because the LGBT respondents were likely to be more sensitive and perceptive in recognizing and describing instances of disrespectful, inadequate and abusive care to LGB patients and their spouses, partners, and surrogates, than heterosexual respondents. In addition, LGB providers may also feel a personal stake in addressing bias based on sexual orientation or gender identity, expecting respectful and affirming palliative care for themselves and their families.

The strengths of the study were having a large sample that includes all the professions on the core palliative care team. The sample is also diverse by geographic region, practice setting, urbanicity, religiosity/spirituality, age, and gender. The measures distinguished between LGB and transgender persons, which is often not done in research on LGBTQ populations.

Future research

This study described the disrespectful, inadequate, and abusive experiences in receiving palliative and end-of-life care of LGB patients and their spouses and partners due to their sexual minority status through the observations of palliative care professionals. Future studies should elicit these reports directly from the LGB patients and their spouses and partners. Bisexual persons should be specifically recruited in order to adequately describe their experiences.

Research should also be conducted to determine the most effective way to change knowledge, attitudes, and behaviors of professional and support staff toward LGB patients. The training should be evaluated to determine the content and modality that results in sustained improvements in providing competent care and increasing comfort in working with LGB patients, and how these may differ by the job type of the individuals trained. Quality improvement projects that are targeted to evaluate the consumer satisfaction of LGB patients regarding the perceived competence and sensitivity of providers to treat them would also be valuable.

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Competing interest. The authors have no conflicts of interest to declare.

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