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Disrespectful and inadequate palliative care to transgender persons

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Abstract

Objectives. The purpose of this study was to describe disrespectful, inadequate, and abusive care to seriously ill patients who identify as transgender and their partners.

Methods. A cross-sectional mixed methods study was conducted. The sample included 865 nurses, physicians, social workers, and chaplains. Respondents were asked whether they had observed disrespectful, inadequate, or abusive care due to the patient being transgender and to describe such care.

Results. Of the 21.3% of participants who reported observing discriminatory care to a transgender patient, 85.3% had observed disrespectful care, 35.9% inadequate care, and 10.3% abusive care. Disrespectful care included insensitivity; rudeness, ridicule, and gossip by staff; not acknowledging or accepting the patient's gender identity or expression; privacy violations; misgendering; and using the incorrect name. Inadequate care included denying, delaying, or rushing care; ignorance of appropriate medical and other care; and marginalizing or ignoring the spouse/partner.

Significance of results. These findings illustrate discrimination faced by seriously ill transgender patients and their spouse/partners. Providers who are disrespectful may also deliver inadequate care to transgender patients, which may result in mistrust of providers and the health-care system. Inadequate care due to a patient's or spouse's/partner's gender identity is particularly serious. Dismissing spouses/partners as decision-makers or conferring with biological family members against the patient's wishes may result in unwanted care and constitute a Health Insurance Portability and Accountability Act of 1996 (HIPAA) violation. Institutional policies and practices should be assessed to determine the degree to which they are affirming to both patients and staff, and revised if needed. Federal and state civil rights legislation protecting the LGBTQ+ community are needed, particularly given the rampant transphobic legislation and the majority of states lacking civil rights laws protecting LGBTQ+ people. Training healthcare professionals and staff to become competent and comfortable treating transgender patients is critical to providing optimal care for these seriously ill patients and their spouse/partner.

Introduction

People who identify as transgender have historically been a marginalized population who have experienced abuse and violence (James et al. 2016; Witten and Eyler 2012), including from healthcare providers (Fredriksen-Goldsen et al. 2014a; James et al. 2016; Kidd and Witten 2008; Redman 2011). Discrimination from healthcare workers in all areas of health care (Grant et al. 2011; Witten 2007) has led to fear and avoidance in seeking health care. About a third have had negative experiences with a healthcare provider and 23% did not see a healthcare provider due to fear of mistreatment (James et al. 2016). Underutilization of health care is highest for individuals who identify as transgender who report higher rates of maltreatment in healthcare settings, including denial of medical care (James et al. 2016; Kosenko et al. 2013).

There is scant data about access, delivery, and quality of hospice and palliative care for individuals who identify as transgender (Choi and Meyer 2016; Witten 2014). Care of these patients is limited or missing from the training of healthcare professionals due to stigma against them, leading to ambivalence and uncertainty in encounters with patients who identify as transgender, mistrust of healthcare providers, and the assumption of patients that providers will not know how to care for them (Grant et al. 2011; James et al. 2016; Poteat et al. 2013). Underutilization of health care is also due to the high likelihood of being uninsured and experiencing cost-related barriers to care compared with persons who are not transgender (Koma et al. 2020).

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, 64.3% thought that patients who identify as transgender were more likely than those who do not to experience discrimination at their institutions and 21.3% observed discriminatory care toward people who identify as transgender. Spouses and partners experienced similar levels of discrimination – respondents observed spouses/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 disrespectful, inadequate, or abusive hospice and palliative care received by patients who identify as transgender, as well as by their spouses, partners, and healthcare surrogates, due to their gender minority status.

Methods

Study design

A cross-sectional mixed methods study was conducted. An online survey was used to collect data. Institutional review board approval was obtained from both Albert Einstein College of Medicine/Yeshiva University (IRB no. 2018-8750) and Fordham University (no. 1057).

Sample

A volunteer sampling method was used to recruit respondents. Nurses, physicians, social workers, and chaplains from seven professional palliative care organizations comprised the study population. The organizations were 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), National Coalition for Hospice and Palliative Care (NCHPC), and Social Work Hospice and Palliative Care Network (SWHPN). Invitations were sent via email to the membership and/or an announcement was posted on the organization website or newsletter. In addition, social workers were invited through an announcement on the SW-PALL-EOL listserv. The National Coalition for Hospice and Palliative Care promoted the study 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 they had observed a patient receiving disrespectful, inadequate, or abusive care due to identifying as transgender. If yes, an open-ended question to describe what they had observed in these instances was asked.

Data analysis

Data were analyzed using a grounded theory approach. The first author read through all the responses and then coded the responses using in vivo coding. A constant comparison analysis was used during initial coding. First-level codes for about one-third of the respondents were jointly reviewed by the first two authors. This was done to eliminate redundancy and to achieve consensus on assigning codes. The first two authors then jointly combined the first-level codes into higher level categories, which were then combined into the final categories for disrespectful, inadequate, and abusive care.

Results

Sample description

The sample of 865 respondents were 37.4% nurses and virtually equal proportions (approximately 20%) of physicians, social workers, and chaplains. Three-quarters were female (75.6%), 22.9% of the sample were males, and 1.5% reported that they were gender nonbinary or gender nonconforming ($n = 10$), transgender ($n = 2$), or were in an unlisted gender group ($n = 2$). There were 30.1% of respondents who reported that they were lesbian, gay, bisexual, or queer.

Respondents had a mean of 18 years (SD = 11.77) of practice experience, of which over 9 years (SD = 7.72) was in palliative and hospice care. Home hospice (27.8%) and working on a palliative care team (27.5%) were the most common work settings. Almost half of the respondents worked in an urban area. All regions of the US were well represented for respondents' workplace, with somewhate fewer in the Southwest. All age groups were represented. The majority of respondents were Protestant, Catholic, or other Christian denomination (63.1%), and most reported that they were very or somewhat religious (85.4%).

Reported prevalence of disrespectful, inadequate, and abusive care to patients who identify as transgender

There were 21.3% who reported that they had observed care in their institution that was disrespectful, inadequate, or abusive to a patient who identifies as transgender. Of these, 85.3% had observed care that was disrespectful, 35.9% had observed care that was inadequate, and 10.3% had observed care that was abusive. The reports of disrespectful, inadequate, and abusive care are presented verbatim, with edits only for typographical spelling errors. Context that is necessary when a phrase or sentence has been taken from a longer quote is provided in brackets.

Although respondents were asked separate questions about disrespectful, inadequate, and abusive care observed, occasionally the behaviors reported for one of these categories appeared to fit better in another category. In describing the results, we included quotes where they fit based on our interpretation of these three categories.

Disrespectful care to patients who identify as transgender

Disrespectful care encompasses a wide range of behaviors, including insensitivity, verbal and nonverbal expressions of being rude, belittling, and disregarding a patient or their spouse, partner, or surrogate due to gender identity and expression.

Not acknowledging or accepting the patient's gender identity and expression

There were numerous reports of staff failing to recognize or ignoring the gender reported by the patient. This included hospital forms with only gender binary choices, questioning the patient's reported gender, discomfort with or discouraging behaviors that would be accepted in patients who do not identify as transgender, and room assignments that were not consistent with the patient's gender.

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All the admission forms use heteronormative language, and binary gender terms.

Disrespectful: asking about "real" gender.

A staff member making negative comments regarding a transgender ED patient-saying the patient should make up their mind regarding gender.

Self-described gender identity not being respected with assignment to a two-bed room.

Patient's chosen family kept asking repeatedly to make sure her wig remained on and every time routine care was performed at the bedside by nursing staff her wig was removed and put away.

One respondent noted that staff were uncomfortable or unprepared for talking with patients who identify as transgender.

Fear of what or how to talk to the patient or how to address them.

There were reports of attempts to control the behavior of patients who identify as transgender.

End-of-life patients being asked not to show public affection.

Another reported that patients who identify as transgender were considered responsible for their illness.

Blaming patient who identified as transgender for current healthcare situation.

Gossip and ridicule

Respondents reported that staff gossiped about and ridiculed patients who identified as transgender based on their gender identity and expression.

During a code situation, staff making jokes about what pronoun to use for the pt.

Saying nasty things at the Nurse's Station.

Jokes related to patient appearance and fashion choices.

Trans man under hospice care developed urinary retention, and the nurse told me that I should check the catheter she had placed because "you've got to see what it looks like."

Comments were made about how to refer to the patient and how to address the patient.

Many jokes made about how to address transgender pts.

Transgender patient referred to as "it".

Statements like, "what are they, male, female?" Or "what do I call 'them'?"

Using inaccurate terms "transvestite."

Insensitive and rude comments made to or within earshot of a patient who identified as transgender

Some of the insensitive or rude comments were directed to the patient or could potentially be overheard by the patient.

I have seen a Fellow ask a pt "so what are you, a boy or a girl?" to a patient.

A dr asking a trans person, "What ARE you?"

A lot of disrespectful chatter by staff in areas where they could easily be overheard

Misgendering

Misgendering was commonly reported. Misgendering occurs when a person who identifies as transgender is referred to or addressed using the wrong pronoun, form of address, or language that does not align with their affirmed gender. Some instances of misgendering appeared to be due to lack of understanding correct and respectful ways of addressing and referring to a person who identifies as transgender.

Failure to use or ignorance of appropriate pronouns or language.

Doctors using incorrect gender when talking about patient in rounds.

Providers constantly use the wrong pronouns for or are insensitive towards their needs.

Most of the reports of misgendering were intentional and occurred even when the staff knew the gender identity and/or name that the patient reported, even after requests from the patient.

Pt's nurse and other caregivers refused to honor pt's gender identity when genitals did not 'match' gender ID.

A trans woman in the ICU was critically ill and dying. Primary bedside nurse refused to use her preferred pronouns.

Addressing only "legally identified" names, gender.

Sometimes staff used pronouns that belittled or mocked the patient.

Person was referred to as "he she."

Transgender patient referred to as "it".

Incorrect name or gender in the medical record

Respondents noted that the medical record sometimes had the incorrect name and/or pronoun for a patient.

RN repeatedly calling transgender patient by their given name which was in the chart, despite patient requesting that she be called by her chosen name.

Patient that asked to be referred to using female pronouns was not. Medical chart also included only use of male pronouns.

Misgendering extended to the patient's spouse/partner.

Staff refusing to use the correct/requested pronoun for the patient or patient's partner.

Case manager had a pt whose partner was transgender and referred to the partner as "it."

Inadequate care to patients who identify as transgender

There were many forms of inadequate care to patients who identify as transgender, including refusing care for these patients, avoiding the patient, ignorance of medical and other domains of providing appropriate care, and discomfort with providing care to a person who identifies as transgender. Another way in which care was inadequate is marginalizing or ignoring the spouse/partner or surrogate.

Refusal to provide care

There were reports of physicians, nurses, and allied health professionals refusing to care for, avoiding, or requesting to be relieved of caring for a patient who identifies as transgender.

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HHA [home health aide] refused to be placed in the home with the patients.

A staff member asking to be removed from caring for the patient.

Co-workers avoiding visits to trans pts or keeping the visits unusually brief, seemingly wishing to avoid their own discomfort, especially male healthcare workers toward male-to-female trans folks.

A doctor who refused to treat a transgender patient saying "I gotta know what's under the hospital gown, I can't take you as a patient," then made jokes about her at staff meeting.

Incomplete care

Care was also described as being incomplete due to the provider's discomfort with patients who identify as transgender.

Some physicians are less enthusiastic, visits are shorter, inquiry into wishes is stunted.

Providers not asking full medical history questions related to sexuality/sexual practices to ascertain risk.

Not asking how patient identifies.

Assumptions that pt is straight or cisgender, or failure to even consider they may not be.

Incomplete care was also attributed to inadequate preparation to treat patients who identify as transgender.

Drs refusing treatment of those involved with hormone therapy because it is "something I don't know anything about and I can't treat you" and lack of physicians who will treat trans people.

In my opinion hospital staff were not well trained in transhealth and still are not.

Insensitive care

Respondents described care that was insensitive to the patient who identifies as transgender.

Providers … are insensitive towards the needs of the transgender patient.

Personal care was insensitive.

Viewing transgender identity as a mental illness

Some respondents reported that transgender identity was viewed as a mental illness by some clinicians.

Transgender patient was 'demonized' … felt patient was mentally sick.

[Providers who] thought transgender was a pathology, and probably bipolar illness.

I heard a supervisor call a transgender patient "crazy."

Violations of privacy

Inadequate treatment included violations of privacy that consisted of revealing personal information about the patient that was unnecessary for other staff to know.

Staff outside the room questioning his choices and how that may have impacted his health issues.

The big issue is lack of privacy or sharing among staff what they've "seen" or not seen. It's often shared as a joke or comical.

The unprofessional responses and questions by staff when a patient was found out to be transgender. That information was shared with others without the patient's consent.

In addition, violations of privacy that included asking unnecessary or voyeuristic questions and examinations.

Asking invasive questions about anatomy, sexual history.

Patient avoiding care or withholding information

There were reports of patients either avoiding care or withholding information from their healthcare provider due to discomfort with providers or fear of being judged.

A patient in the emergency room did not want to take off their clothes for fear of being judged for being transgender. Staff did not take time to listen to this fear and labeled the patient uncooperative.

Patient was not comfortable discussing their healthcare concerns around certain staff.

I have witnessed transgender individuals avoid healthcare completely due to their status.

Ignoring the spouse/partner

There were numerous reports of healthcare providers ignoring the spouse or partner of a patient who identifies as transgender or if the spouse or partner was transgender.

Purposefully dismissing patient's significant other even when recognized by legal union.

Front desk staff misgendering pt's partner and denying entry to the pt.

There were reports of excluding the spouse or partner when the patient wanted them present or excluding them from decision making.

A colleague would not include my pt's partner in exam room and discussion even though pt wanted him present.

Reports included favoring biological family over chosen family and preferred decision-makers.

Estranged family members were compulsively brought in at the end of life for key medical decision making.

Healthcare providers not being aware of same sex partners, in favor of biological family (who may or may not know patient's wishes as well as partner)

Abusive care

Although 10.3% of our provider sample reported observing abusive care, there were only three examples in which abuse was explicitly mentioned. These were:

I witnessed transgendered and nonbinary people experience abusive language.

[I] witnessed verbal abuse and poor patient care … as well as very incompetent care.

Patient felt they were not protected from abuse from other patients and staff.

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Discussion

This study is one of the first to document the varied ways in which hospice and palliative care have been poorly delivered to patients who are transgender. There were 157 participants who reported examples of care that is disrespectful, inadequate, or abusive due to the patient's or spouse's/partner's sexual orientation and 140 who reported discriminatory care towards patients who identified as transgender. These findings amplify and illustrate our quantitative data (Stein et al. 2020) regarding the discrimination faced by seriously ill patients who identify as transgender and their spouses/partners. Fear of encounters with transphobic providers is difficult at any time, but particularly so when one is vulnerable during advanced illness and at end of life.

Approximately 1.6 million Americans (Herman et al. 2022), 0.5% of the US population, identify as transgender, and this community is beset by demeaning acts and discriminatory policies. As of June 15, 2023, there were 491 anti-LGBTQ+ bills introduced in 47 state legislatures (American Civil Liberties Union 2023a), including 118 anti-transgender healthcare bills (American Civil Liberties Union 2023b). A growing number of anti-LGBTQ+ bills have been enacted by Republican-led states, including 20 states enacting bans or severe restrictions on gender-affirming care, primarily impacting minors (Ables 2023; Human Rights Campaign 2023).

Disrespectful care

Disrespectful care may be regarded as less serious than care that is inadequate or abusive. However, it is harmful because it is insulting and hurtful and therefore damaging to patient care. Words, facial expressions, and body language express judgment, disapproval, ridicule, and rejection that are dehumanizing. Patients who identify as transgender experience unique forms of disrespectful health care. There were many reports of ridicule and dehumanizing comments from providers and support staff regarding patient's gender identity and expression. These included misgendering and objectifying their bodies, which simultaneously denies and ridicules their being and identity. Providers who communicate disrespect and ridicule may also deliver inadequate care to patients who identify as transgender. Such behavior is offensive and may result in mistrust of providers and the healthcare system and to delaying or avoiding care or not sharing information with providers that is important for diagnosis and treatment, resulting in poorer physical and mental health outcomes.

Violations of privacy, including unnecessary sharing or gossiping with colleagues, is disrespectful and many may be Health Insurance Portability and Accountability Act of 1996 (HIPAA) violations. Sharing irrelevant information about gender identity or speaking about it when other staff or patients can overhear may be very distressing (ACCESSCareA Team 2017). Finally, disrespect for spouses/partners, such as failing to acknowledge them, disrespecting their decisions, limiting hospital visitation, ridiculing or misgendering, or asking couples to avoid expressions of affection and intimacy, also lead to mistrust of healthcare providers and institutions.

Inadequate care

Inadequate care due to a patient's or spouse's/partner's gender identity is particularly serious and may lead to legal liabilities based on negligence or violations of civil rights or HIPAA laws or Department of Health and Human Services and Medicare policies. This includes care that is denied, delayed, or rushed; avoiding patients or families; inappropriately transferring or dismissing patients; and violations of privacy and confidentiality standards. Dismissing spouses/partners as decision-makers or conferring with biological family members against the patient's wishes may result in undesired care and be a HIPAA violation if they are not the legally-designated healthcare surrogate.

Disrespectful and inadequate care may be due to religious and cultural beliefs or lack of familiarly with people who identify as transgender. It may also result from inadequate training about treating patients who identify as transgender and their spouses/partners, including their unique medical, psychosocial, and legal issues (Maingi et al. 2021).

Implications for policy and practice

Hospice and palliative care programs ideally foster respectful, inclusive, and affirming care for the LGBTQ+ community. Providers should assess their institutional policies and practices to determine the degree to which they are welcoming and affirming to both patients and employees. LGBTQ+ care should include an institutional assessment of nondiscrimination policy, employment policies, intake practices, and community outreach and marketing (Acquaviva 2017).

Nondiscrimination policy

The findings from this study bolster the need for federal and state civil rights legislation protecting the LGBTQ+ community where they do not exist. Currently, civil rights laws protecting LGBTQ+ people exist in only 22 states, primarily in the Northeast, West Coast, Midwest, and the District of Columbia (Movement Advancement Project, SAGE and Center for American Progress 2023). While the federal Equality Act awaits passage by Congress Equality Act 2021), the US Supreme Court expanded the definition of gender in employment cases brought under federal civil rights law to include sexual orientation and gender identity (Bostock v. Clayton County 2020). This same reasoning may be extended to public accommodations discrimination, which applies to health-care providers. Institutional policy should abide by policies to protect LGBTQ+ patients and employees from discrimination (Department of Health and Human Services 2022), including strategies to identify, report, and respond to discriminatory care.

Training

Lack of training on treating patients who identify as transgender was mentioned by respondents as the cause of avoiding care for them and providing inadequate treatment. Care of patients who identify as transgender is limited or missing from the training of healthcare professionals due to stigma against them, leading to ambivalence and uncertainty in encounters with them and the assumption of these patients that providers will provide incompetent or insensitive care for them (James et al. 2016; Poteat et al. 2013). Prior research has found that providers lacked familiarity with clinical issues related to their gender history and interactions between treatments for gender expression and advanced illness (ACCESSCareA Team 2017; Bristowe et al. 2018). Patients desired

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to die as the gender they identify with, requiring healthcare professionals to be knowledgeable about these interactions between treatments for the illness and for gender identity preservation.

Our data support the need for training of healthcare professionals to become sensitive, competent, and comfortable in treating patients who identify as transgender. Guidelines for best practices with these patients (Acquaviva 2017; Eckstrand and Ehrenfeld 2016; Fredriksen-Goldsen et al. 2014b) should be incorporated into training to increase awareness of their physical and psychosocial issues (Alpert et al. 2017). All members of the core palliative and hospice care team, in addition to staff who work closely with patients, such as home health aides and certified nursing assistants, should receive training. Support staff who are not involved in patient care but who interact with patients, such as transport workers and housekeeping, should also be trained to interact respectfully and sensitively with patients who identify as transgender. Staff members who participated in cultural competency training felt better prepared to discuss gender identity and sexual orientation relevant to care (Bristol et al. 2018). Training paraprofessionals who will be providing intimate care is particularly important (Bristowe et al. 2018).

Intake and outreach

Policies at the institution or agency should explicitly include people who are transgender. Printed and visual materials used for patient information and education should reflect them (Acquaviva 2017). All forms should be revised to be inclusive of nonbinary gender identity and provide the opportunity for patients to enter their preferred pronouns and the name they choose to be called if different from their legal name. The medical record should include this information, and all staff should be trained to use the pronouns and names preferred by the patient. There are numerous resources to guide institutional policy (The Joint Commission 2011; World Professional Association for Transgender Health 2021).

Strengths and limitations

The nonprobability sampling plan resulted in selection bias. Lesbian, gay, bisexual, and queer respondents comprised 30% of the sample, which is approximately 10 times higher than their estimated proportion in the US (Gates 2011). However, these respondents may have been more perceptive than heterosexual respondents in identifying and reporting poor care to patients who identify as transgender and their spouses, partners, and surrogates. Having only two respondents in the sample who self-identified as transgender does not allow for making any meaningful statements based on their observations. Another limitation was the lack of depth in the qualitative data reported here. Using a self-administered survey, it was not possible to probe for more detail about the contextual aspects of the discriminatory care that was observed.

There were several important strengths of this study. The large national sample included representation from nursing, medicine, social work and chaplaincy,. Respondents were from all geographic regions of the US, from several practice settings, and varied by urbanicity, religiosity/spirituality, age, and gender. While most studies about the experience of LGBTQ+ patients do not distinguish between LGB and patients who identify as transgender, experiences of disrespectful, inadequate, and abusive treatment were assessed separately for these two groups.

Future research

Future studies should include adequate numbers of providers who identify as transgender to gain insights from their observations of the experience of their patients who identify as transgender. More importantly, studies including transgender patients and their spouses/partners are needed to learn firsthand of their experiences receiving hospice and palliative care.

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