

Original Article

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Author for correspondence:

Kristin G. Cloyes,
College of Nursing, University of Utah,
Salt Lake City, UT, USA.
E-mail: kristin.cloyes@nurs.utah.edu

Providing home hospice care for LGBTQ+ patients and caregivers: Perceptions and opinions of hospice interdisciplinary care team providers

Kristin G. Cloyes, PH.D., M.N., R.N.¹ , Miranda Jones, B.S.¹, Caroline Gettens, B.S.N., R.N.², Sarah E. Wawrzynski, PH.D., B.S.N., R.N.¹ , Sara Bybee, PH.D., L.C.S.W.¹, Djin L. Tay, PH.D., R.N.¹, Maija Reblin, PH.D.³  and Lee Ellington, PH.D.¹

¹College of Nursing, University of Utah, Salt Lake City, UT; ²School of Nursing, Simmons University, Boston, MA and

³Health Outcomes & Behavior, Moffitt Cancer Center, Tampa, FL

Abstract

Objectives. Hospice patients and caregivers who are members of sexual and gender minority groups (i.e., LGBTQ+) have reported experiencing unmet needs at end of life (EOL). Negative experiences often stem from challenging interactions with healthcare providers due to ineffective or poor communication and providers' heteronormative assumptions and biases. Few studies, however, examine hospice care team (HCT) providers' knowledge, experience, and opinions related to EOL care for LGBTQ+ patients and caregivers despite this being identified as a gap in competency and education. We sought to examine HCT providers' perceptions regarding (1) awareness of LGBTQ+ patients and caregivers; (2) knowledge of specific or unique needs; and (3) opinions on best care and communication practices.

Methods. Six focus groups conducted with HCT providers ($n = 48$) currently delivering hospice care in three US states were audio-recorded and transcribed. Data were content coded ($\kappa = 0.77$), aggregated by topical categories, and descriptively summarized.

Results. Participants were mostly white and non-Hispanic ($n = 43$, 89.6%), cisgender female ($n = 42$, 87.5%), heterosexual ($n = 35$, 72.9%), and religious ($n = 33$, 68.8%); they averaged 49 years of age (range 26–72, $SD = 11.66$). Awareness of LGBTQ+ patients and caregivers depended on patient or caregiver self-disclosure and contextual cues; orientation and gender identity data were not routinely collected. Many viewed being LGBTQ+ as private, irrelevant to care, and not a basis for people having specific or unique EOL needs because they saw EOL processes as universal, and believed that they treat everyone equally. Providers were more comfortable with patients of lesbian or gay orientation and reported less comfort and limited experience caring for transgender and gender-diverse patients or caregivers.

Significance of results. Many HCT members were unaware of specific issues impacting the EOL experiences of LGBTQ+ patients and caregivers, or how these experiences may inform important care and communication needs at EOL.

Introduction

Engagement of hospice services is often driven by a patient's desire to die at home, in the company of family and close others (Hamel et al., 2017). In the US, 98% of hospice care is delivered in the patient's home or residence (National Hospice and Palliative Care Organization, 2020) where informal primary caregivers, often family members, provide 24/7 care supported by hospice care team (HCT) providers (Wolff et al., 2020). Within the personal, intimate spaces of patients, HCT members interact with the people who are central to patients' lives (Ellington et al., 2013; Cloyes et al., 2014), navigating the relationships and interactions that comprise family (as defined by the patient) dynamics (Ferrell et al., 2015; Guo et al., 2019).

Home hospice care, therefore, requires that providers possess considerable clinical and communication skills as effective communication is essential to optimal end-of-life (EOL) outcomes (Wittenberg-Lyles et al., 2012; Clayton et al., 2014; Bhatt and Mitchell, 2015; Dingley et al., 2017; Ellington et al., 2018; Back, 2020). Ideally, these skills are informed by up-to-date knowledge, standards of practice, and personal insight built upon clinical experience and critical reflection (Ferrell et al., 2015). Poor communication negatively impacts patient and family EOL experiences and psychosocial outcomes (Cloyes et al., 2014) sometimes with lasting effects for caregivers and close others (Moore et al., 2016).

Research conducted across healthcare settings indicates that providers' lack of knowledge, experience, and both explicit and implicit biases often negatively impact interactions with minoritized individuals, including those who identify as LGBTQ+ (Eliason and Dibble,

2015; Elk and Boehmer, 2015; Bristowe et al., 2016; Cloyes, 2016; Floyd et al., 2016; Haviland et al., 2020; Deliz et al., 2020; Edmonds, 2020; Webster and Drury-Smith, 2020; Westwood et al., 2020). LGBTQ+ patients and caregivers have reported experiencing discrimination and bias during encounters within healthcare systems, (Smolinski and Colón, 2006; Chidiac and Connolly, 2016; Brooks et al., 2018; Brown and McElroy, 2018; Kortés-Miller et al., 2018; Waling et al., 2019; Candrian and Cloyes, 2020; Cloyes et al., 2020; Haviland et al., 2020; Stein et al., 2020; Sutter et al., 2020; Valenti et al., 2020) which reinforce hetero- and cisnormative assumptions about personhood, relationships, and families, and can be invalidating (Cloyes et al., 2018; Kilicaslan and Petrakis, 2019). These experiences can lead LGBTQ+ patients to mistrust health care providers, anticipate mistreatment and discrimination, and avoid health care encounters, resulting in delays in diagnosis and treatment (Eliason and Dibble, 2015; Elk and Boehmer, 2015; Haviland et al., 2020). LGBTQ+ patients may also choose not to share details of their personal life and history with providers (Smolinski and Colón, 2006; Chidiac and Connolly, 2016; Jacobson, 2017; Brown and McElroy, 2018; Candrian and Cloyes, 2020) making it difficult for providers to assess and discuss aspects of patients' lives that have a direct bearing on managing life-limiting illness and goals of care (Brooks et al., 2018).

This home setting of hospice care may heighten these dynamics, yet limited empirical research examines how HCT providers' knowledge, opinions, and assumptions translate into beliefs and behaviors that impact communication and care in the home setting. The purpose of this study was to describe the knowledge, experience, and opinions of HCT providers concerning the provision of in-home hospice care to LGBTQ+ patients and family caregivers

Methods

We conducted focus groups to explore HCT providers' knowledge and opinions in four areas of focus: (1) awareness of LGBTQ+ hospice patients and caregivers; (2) knowledge of factors that may influence EOL experiences of LGBTQ+ patients and caregivers; (3) opinions regarding whether LGBTQ+ patients and caregivers have specific or unique care needs; and (4) perceptions of best practices for providing competent and inclusive care. Study activities were approved by the university Institutional Review Board for the protection of human subjects.

Sampling and recruitment

We recruited HCT providers working in three hospice agency research partners in geographically diverse US states: a northeastern state (NE), a southeastern state (SE), and an intermountain west state (IMW). Eligible participants were 18 years of age or older, able to speak and read English, employed by a partner agency at the time of the study, and actively involved in providing home hospice services.

Agency partners helped us distribute informational flyers and emails via their routine internal communication channels, and our on-site study coordinators circulated and managed sign-up sheets of interested HCT providers. Participant enrollment information was not shared with hospice agency leadership.

Data collection

Setting

Six focus groups were hosted on-site in the offices of the participating agencies (three at the NE site, two at the IMW site, and one at the SE site.) All focus groups occurred after-hours in meeting rooms at partner agencies' central offices.

Procedures

Focus groups were scheduled for 90 min and facilitated by a research team member (KGC) following a semi-structured question guide. Participants completed informed consent and a brief survey collecting data on demographics and hospice-related work history. All groups were audio-recorded. Participants received a \$50 gift card and a meal.

Data analysis

All audio recordings were professionally transcribed and imported into NVivo software for coding. We followed a qualitative descriptive approach (Kim et al., 2017; Doyle et al., 2020) combining iterative stages of directed and inductive content analysis. First, all members of our coding team used *a priori* topic codes in the four areas of focus to label a subset of data from each site. Reliability statistics (Kappas) were calculated to assess the level of intercoder agreement, results of initial topical coding were discussed, discrepancies were resolved by team consensus, and the codebook was refined. This process was repeated until a substantial level of agreement was reached ($\kappa = 0.77$; McHugh, 2012). Thereafter, coding team members individually coded the remaining focus group data following the codebook. Data were then aggregated by topic, reviewed by the team, and inductively coded for patterns in content. Results were reviewed and discussed by the team and narratively summarized.

Results

Our report describes the participants' responses within each of the four areas of focus. Table 1 presents demographic data on HCT focus group participants ($N = 48$) by study site. Table 2 presents sub-categories and illustrative participant quotes.

Participant demographics

The average age of participants was 49.23, most were white (89.6%), not Hispanic/Latinx (89.6%), female (87.5%), heterosexual (72.9%), cisgender (100%), married or partnered in a committed relationship (56.3%), religious (70.3%) and had five or more years of post-high school education (39.6%; Table 1). Nurses were the largest subgroup of participants (37.5%) followed by social workers (18.75%) and hospice aides (14.6%). On average, HCT providers had worked in their current hospice positions for 5.29 years; most did not have other specialized hospice or palliative care training outside of their organization (70.8%).

Awareness of LGBTQ+ hospice patients and caregivers

HCT providers discussed three ways in which they became aware of serving LGBTQ+ patients: formal documentation and communication of patients' sexual orientation and gender identity (SOGI) and relationship; patient or caregiver self-disclosure; and reliance on indirect assessment and inference.

Table 1. Demographic characteristics of HCT provider participants

Demographics	Overall Sample (N = 48)		IMW (n = 14)		NE (n = 23)		SE (n = 11)	
	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Age	49.23 (11.66)	26–72	46.36 (10.93)	34.00–65.00	50.87 (11.61)	26.00–69.00	49.45 (13.03)	27.00–72.00
Number of Dependent Children	0.74 (1.13)	0–4	1.00 (1.47)	0–4	0.48 (0.79)	0–2.00	1.67 (1.15)	1–3
Years worked in Current Position	6.60 (6.26)	0.25–30.00	8.08 (5.57)	2.00–19.00	4.30 (4.10)	0.25–17.00	9.8 (9.27)	1.00–30.00
Years worked in Current Hospice	5.29 (4.68)	0.25–18.00	5.33 (3.35)	0.50 (14.00)	4.24 (4.76)	0.25–18.00	7.68 (5.57)	2.00–17.00
	N (%)		n (%)		n (%)		n (%)	
Race								
White	43 (87.76)		14 (100.00)		22 (95.65)		7 (63.64)	
Black or African American	4 (8.16)		0 (0.00)		0 (0.00)		4 (36.36)	
Asian	1 (2.04)		0 (0.00)		1 (4.35)		0 (0.00)	
Missing	1 (2.04)		0 (0.00)		0 (0.00)		0 (0.00)	
Ethnicity								
Hispanic/Latino	4 (8.33)		2 (14.29)		2 (8.70)		0 (0.00)	
Non-Hispanic/Latino	43 (89.58)		12 (85.71)		20 (86.96)		11 (100.00)	
Missing	1 (2.08)		0 (0.00)		1 (4.35)		0 (0.00)	
Gender								
Female	42 (87.50)		12 (85.71)		21 (91.30)		9 (81.82)	
Male	6 (12.50)		2 (14.29)		2 (8.70)		2 (18.18)	
Prefer to self-describe	0 (0.00)		0 (0.00)		0 (0.00)		0 (0.00)	
Prefer not to say	0 (0.00)		0 (0.00)		0 (0.00)		0 (0.00)	
Cis- or Transgender								
Cisgender	48 (100.00)		14 (100.00)		23 (100.00)		11 (100.00)	
Transgender	0 (0.00)		0 (0.00)		0 (0.00)		0 (0.00)	
Sexual Orientation								
Heterosexual/Straight	35 (72.92)		10 (71.43)		15 (65.22)		10 (90.91)	
Lesbian/Gay	9 (18.75)		0 (0.00)		8 (34.78)		1 (9.09)	
Bisexual	1 (2.08)		1 (7.14)		0 (0.00)		0 (0.00)	
Missing	3 (6.25)		3 (21.43)		0 (0.00)		(0.00)	
Relationship Status								
Married	17 (35.42)		7 (50.00)		7 (30.43)		5 (45.45)	
Domestic Partnership/Civil Union	8 (16.67)		0 (0.00)		1 (4.35)		1 (9.09)	

(Continued)

Table 1. (Continued.)

Demographics	Overall Sample (N = 48)		IMW (n = 14)		NE (n = 23)		SE (n = 11)	
	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Committed Relationship	8 (16.67)		2 (14.29)		5 (21.74)		1 (9.09)	
Single (Never Married)	6 (12.50)		3 (21.43)		2 (8.70)		1 (9.09)	
Separated/Divorced	11 (22.92)		1 (7.14)		7 (30.43)		3 (27.27)	
Widowed	2 (4.17)		1 (7.14)		1 (4.35)		0 (0.00)	
Missing	2 (4.17)		2 (14.29)		0 (0.00)		0 (0.00)	
Religious Preference								
No religious preference	12 (25.00)		4 (28.57)		5 (21.74)		3 (27.27)	
Catholic	11 (22.92)		1 (7.14)		8 (34.78)		2 (18.18)	
Latter Day Saint	6 (12.50)		6 (42.86)		0 (0.00)		0 (0.00)	
Protestant	11 (22.92)		4 (28.57)		5 (21.74)		3 (27.27)	
Jewish	1 (2.08)		0 (0.00)		1 (4.35)		0 (0.00)	
Other ^a	4 (8.33)		0 (0.00)		3 (13.04)		1 (9.09)	
Missing	3 (6.25)		0 (0.00)		1 (4.35)		2 (18.18)	
Years of Post-High School Education								
1–2	12 (25.00)		5 (35.71)		3 (13.04)		4 (36.36)	
3–4	12 (25.00)		4 (28.57)		5 (21.74)		3 (27.27)	
5 or more	19 (39.58)		4 (28.57)		14 (60.87)		1 (9.09)	
Missing	5 (10.42)		1 (7.14)		1 (4.35)		3 (27.27)	
Current Position or Role in Hospice								
Aide/Nurse/Nurse Case Manager	24 (50.00)		7 (50.00)		11 (47.83)		6 (54.55)	
Social Worker/Counselors	10 (20.83)		3 (21.43)		7 (30.43)		0 (0.00)	
Non-RN Coordinator/Manager	7 (14.58)		3 (21.43)		1 (4.35)		3 (27.27)	
Chaplain	5 (10.42)		1 (7.14)		3 (13.04)		1 (9.09)	
Music Therapist	1 (2.08)		0 (0.00)		1 (4.35)		0 (0.00)	
Missing	1 (2.08)		0 (0.00)		0 (0.00)		1 (9.09)	

^aFour participants indicated having an “other” religion, but did not provide description in the free-text field. Two participants responded having an “other” religion, and described Episcopalian and Christian in the free text, which was recoded as “Protestant”.

Table 2. Categories of HCT providers' responses with exemplary participant quotes

Category of Analysis	Subcategories	Exemplar Quotes
Awareness of LGBTQ+ Hospice Patients and Caregivers	• Documentation of SOGI information	<i>I've been here about three years and I know that that's a question on the form and that people are encouraged to, you know, ask all the questions, but the whole time I've been here we've never had a training, like a refresher even on the various questions that we ask.</i>
	• Disclosure	<i>I had one woman with dementia who thought I was her long-lost partner when I walked in the room. She was like "You came back! Oh my god." And we had this whole thing where I spent the next hour trying to figure out who I was to her in her dementia. So that's how she came out to me.</i>
	• Indirect assessment and inference	<i>He's not one that I would just be like "Oh yeah!" That's not something that I would just pick up from him right away, because he's not ... he wasn't necessarily stereotypically [gay].</i>
Knowledge of Factors Influencing EOL Experiences for LGBTQ+ Patients and Caregivers	• Competency training	<i>I think maybe the training would need to be on bias, identifying your own bias as it relates to not just the gay and lesbian population but to any of it. People of color, people of different religions, maybe a bias training to get people to tap into that as opposed to specific to — because it's all those things that are going to come up, not just the fact if they're gay or not.</i>
	• Prior experience	<i>As a caregiver, my mother-in-law was on hospice and we felt super vulnerable to have people come in the house who we didn't know, even though I trust hospice people because I work in hospice. But still, my mother-in-law was straight, but we're not, and she didn't know if people would be okay with who her daughter is.</i>
	• Caring for transgender and gender-diverse patients and caregivers	<i>It wasn't really until our last session together that she actually came out as a trans woman to me, and I had been using male pronouns the whole time. She hadn't asked me at the time, and then finally she said "Can you actually call me by this name? And if you ever see me again, please use this name instead, and these pronouns." And that's what I went with. It's important to me if it's important to them.</i>
Opinions on Whether LGBTQ+ Patients and Caregivers Have Specific or Unique Needs	• LGBTQ+ hospice patients and caregivers <u>do not</u> have specific or unique EOL needs	<i>They're a human being who is coming to the end of their life. What they believe — what their sexual orientation is, any of those things are second. If they want to share with us, that's wonderful. I feel like that's a gift they help give us. But to think it should make a difference in any way, I'm sorry, I just don't think it should.</i>
	• LGBTQ+ hospice patients and caregivers <u>do</u> have specific or unique EOL needs	<i>When you're in such a vulnerable place as a patient, when you feel super-vulnerable it takes one tiny glance or one tinge comment when you're feeling that kind of vulnerable to completely shut down any communication.</i>
Best Care and Communication Practices with LGBTQ+ Patients and Caregivers	• Establishing trust and signaling "safe" space	<i>I wear the little pin in my lanyard, the rainbow pin, to just give them a sense that I'm an ally.</i>
	• Treating everyone the same	<i>Maybe what we need to do to be good providers and provide good care to everyone is to look at ourselves and what our internal biases are and how we can put them behind us to provide good care, no matter who we're dealing with. It's all about caring for [patients]. It's all about love. The work we do is love.</i>

Documentation of SOGI information

At two of the three sites (SE and IMW) participants stated that neither SOGI data nor other information related to whether patients are LGBTQ+ was systematically collected by their agencies. Participants at the NE site thought this information was assessed on intake, yet they were generally unsure of when this information was collected, whether it was routinely collected, and where in the patients' records it was recorded.

In the absence of documented SOGI, some providers would use specific terms such as "partner" or "significant other" in intake documentation to signal that a patient was in a same-sex relationship. This practice was often part of a process in which providers pieced together information from patient files and

informal verbal reports from other providers. A hospice nurse described this occurring before her initial home visit with an LGBTQ+ patient: "I was called by the nurse manager and she was telling me a little bit about the woman, and I found out through this and the information she sent me that she lives with her partner. This tends to be the normal word that everybody puts."

Disclosure

The majority of participants considered patient or caregiver self-disclosure to be the ideal path to provider awareness because this was seen as indicative of trust, an element that all HCT providers believed was essential to optimal EOL care: "They just have to get

to that place where they feel they can trust you.” Patient or caregiver self-disclosure was also seen by providers as evidence that the person felt that being LGBTQ+ was relevant to their EOL experience and hospice care, and therefore important information for the provider to know. Not self-disclosing was interpreted as a signal that patients and caregivers did not want providers to know (“It’s part of the privacy thing”), did not feel it was pertinent (“If someone wants us to know, they’ll find a way to tell us”), or both.

Several LGBTQ+ participants shared how they would disclose being LGBTQ+, or having LGBTQ+ family members, as a way to signal awareness and safety. If patients or caregivers had not previously disclosed being LGBTQ+, providers found ways to casually bring up related themes in conversation (e.g., attending a same-sex wedding, having an LGBTQ+ child). If the patient or caregiver did self-disclose being LGBTQ+, LGBTQ+ participants said they disclosed in turn, again to signal safety and affiliation. A lesbian provider felt this was important “because I also identify as a lesbian, if somebody comes out to me I come out immediately because I feel like my experience in health care tells me that I need to be cautious until I know somebody’s safe.”

Indirect assessment and inference

Most HCT providers were concerned that more direct engagement could alienate patients and families, particularly older adults. Some reasoned that even if an older adult was LGBTQ+, asking about or discussing this could make them feel exposed and less safe, leading to erosion of trust. Because of this, participants described the need to be able to “read” cues sent by patients, caregivers, or other family members, which may have been disclosed unintentionally or intentionally; one provider stated that “people seem to leak out certain words or make certain references.”

Many participants described looking for environmental cues such as pictures, books, objects, or décor that providers would typically associate with someone of a different gender, and the layout of personal space such as sleeping arrangements. More than one participant described individuals’ appearance, behaviors, and mannerisms as another important cue when these did not fit typical binary gender stereotypes: “If there’s not a partner and they’re still gay or transgender, then probably that’s just what I would look for, is just a non-stereotypical behavior if they’re a male or female.”

Knowledge of factors influencing EOL experiences for LGBTQ+ patients and caregivers

Participants reported that their knowledge about LGBTQ+ individuals mainly came from two sources: LGBTQ+ competency training provided by their hospice organization and prior clinical experiences with LGBTQ+ patients and families. Participants across all sites raised their lack of knowledge of transgender and gender-diverse patients as an area of educational need.

Competency training

Only providers at the NE site reported receiving any LGBTQ+ focused in-services or competency training through their hospice organization. These sessions focused on historical and cultural events related to systematic bias and discrimination and on LGBTQ+ terminology and definitions such as the difference between sexual orientation and gender identity. A number of those who received this training also noted that while helpful, they also wanted more information on specific, concrete assessment and communication techniques that are more LGBTQ+ sensitive and inclusive.

Prior experience

Many HCT providers reported that they had previous experience caring for LGBTQ+ patients; only a few participants in any of the groups stated they had none; a number of these accounts related to caring for patients with histories of HIV/AIDS. In the NE and IMW groups, participants reflected that caring for patients with HIV/AIDS had likely shaped their understanding and practices as individual providers. Many HCT providers also discussed how they generalized what they had learned from their past experiences with specific LGBTQ+ patients and caregivers. In contrast, LGBTQ+ participants tended not to describe their own personal or past clinical experiences as generalizable, and instead discussed how it sensitized them to the importance of learning more about individual patients’ and caregivers’ situations and needs.

Caring for transgender and gender-diverse patients and caregivers

One of the most broadly endorsed points raised was a lack of knowledge and experience related to caring for transgender and gender-diverse patients. Some HCT participants seemed to assume that transgender and gender diverse patients would experience more mental health issues and trauma than cisgender and binary individuals, which they thought would complicate both physical care and interpersonal communication. Much of this conversation focused on the medical and social histories of transgender patients as being “complex” and gender diversity as being “new” and the proliferation of potential identities that were “hard to keep up with.”

HCT providers’ opinions on whether LGBTQ+ people have specific or unique EOL needs

HCT providers differed in their opinions on whether or not LGBTQ+ patients and caregivers have specific or unique EOL care and communication needs compared with those who are not LGBTQ+. The majority of participants in the IMW and SE focus groups asserted that there was no difference, while more participants in the NE site thought there were differences. Opinions were connected to participants’ perceived relevance of being LGBTQ+ to EOL experiences and care.

LGBTQ± hospice patients and caregivers do not have specific or unique EOL needs

Those who believed this cited death as the “great equalizer” and a “common denominator” of human experience and the universality of EOL processes as chief reasons why LGBTQ+ people do not have specific or unique care needs: “They’re a human being who is coming to the end of their life. What they believe — what their sexual orientation is, any of those things are second.” These HCT providers also identified common topics, such as reconciliation with family of origin, that they saw as crosscutting EOL concerns and processes for patients, based on circumstances rather than subjectivity, in ways that made people’s orientation or gender secondary considerations at most:

What about a family who, because somebody is gay, the parents have estranged the child and now the child is dying and wants to reach out to their parents. Again, that doesn’t have to do with their sexuality. It has to do with family circumstances. The sexuality is what caused the rift, but we’re addressing the rift and we’re addressing the person. It doesn’t make a difference. A problem is a problem is a problem.

LGBTQ± hospice patients and caregivers do have specific or unique EOL needs

Within each focus group, there were a few HCT providers who argued that the systematic historical and structural discrimination experienced by LGBTQ+ communities impact EOL outcomes and needs, and noted issues related to barriers to legally recognized unions (e.g., marriage, civil unions), disparities in access to medical information and insurance coverage, and differences in family structures and social support systems. As one HCT member said: “There are practical pieces that come into play a little differently than maybe they do for traditional [heterosexual married] couples. It’s not ‘are your affairs in order’ because your affairs might be a little different, or needing to take a little different turn to make sure these things can happen for you in the way they’re supposed to like they do for everybody else.”

These providers also pointed out how the intimate nature of home hospice care created complex and multi-layered vulnerability:

For anyone who is accepting hospice, it’s really allowing a bunch of strangers to come in at a really vulnerable time, and for you to share your life with them and your hardships and what’s not going well, and your fears. So, if you add a caregiver that has to worry “Are these people going to be accepting, and how comfortable do I feel sharing this stuff?” I think there’s an extra layer of just wondering about communication. Every single person who comes into your home, you have to worry about that, every single time. That’s an extra layer of stress.

One LGBTQ+ HCT provider at the NE site connected these points to the idea of heteronormativity, suggesting that non-LGBTQ+ HCT providers may not feel that orientation or gender identity are of primary importance or significance because they are so used to experiencing their own heterosexual and cisgender status as an unquestioned, unchallenged standard or “the norm.”

Best care and communication practices with LGBTQ+ patients and caregivers

Much of what HCT providers said about best care and communication practices was general and applicable to all hospice patients and caregivers, although there were a few frequently mentioned practices that were seen as being LGBTQ+ specific.

Establishing trust and signaling a “safe” space

In every focus group, HCT providers talked about the need to establish trust with patients and family caregivers and to create a space where they could feel safe and “accepted for who they are.” Participants’ descriptions of how they accomplished this largely focused on providing the same level and quality of care and not differentiating their communication or practice based on anyone’s presentation or history. This was described as an essential principle of hospice and a basic ethical stance: providing equal care, with respect, while also “meeting every person where they are at” in the EOL process.

When HCT providers did identify best practices that were specific to LGBTQ+ patients or caregivers, the behaviors mentioned most frequently included wearing rainbow pins or emblems; making conversation that signals openness and acceptance of LGBTQ+ groups (e.g., talking about providers’ own LGBTQ+ family members or friends); and using the correct language to refer to significant relationships such as “partner” or “spouse.”

Treating everyone the same

A majority of participants across all sites talked about their belief that they provide the same high-quality care to all their patients

and their families, regardless of who the patient is or who is present during the EOL process; the phrases “I treat them [patients] like my own family” or “like I would want my family treated” were repeated multiple times across all sites. Moreover, this assertion was presented as not only a clinical but also an ethical standard for the field of EOL care. Based on this, HCT providers rejected the idea that LGBTQ+ patients and caregivers may have different or specific EOL considerations as antithetical to a basic premise of equal treatment. A hospice aide at the SE site summarized this sentiment: “I don’t think it’s important. I treat everybody the same. When I go to houses or homes or nursing homes, whatever, I don’t look for [sexual or gender] preference. I just treat it like you are like a person.”

Discussion

Our findings represent the responses of HCT providers in geographically diverse regions of the US. Despite differences in region and professional roles, we found similarities in how participants described working with LGBTQ+ patients and family members, their knowledge regarding factors that may influence the EOL experiences of LGBTQ+ patients and caregivers, their opinions on whether LGBTQ+ patients and caregivers have specific or unique EOL care needs as compared with non-LGBT+ people, and their perspectives on best care and communication practices. In what follows, we summarize our findings in relation to recommendations to promote LGBTQ+ competent and inclusive hospice and EOL care.

Implications for practice: SOGI data, assessment, and disclosure

Many of our participants did not believe that SOGI data should be routinely collected or documented, arguing that both orientation and gender are “private” concerns that do not factor into EOL care and that patients and caregivers would perceive such assessment as intrusive. This sentiment conflicts with previous research showing that individuals are willing to provide orientation and gender identity data (Fredriksen-Goldsen and Kim, 2015; Ruben et al., 2017) especially if they believe this will lead to improved care. Many also believed that patients and caregivers would prefer to verbally disclose being LGBTQ+ although again, prior research indicates a preference on behalf of both patients and providers for nonverbal disclosure along with other demographic and relevant health information via a standardized self-report tool such as an intake form (Haider et al., 2017).

While many HCT providers saw self-disclosure as empowering or a sign of trust placed in the HCT provider, LGBTQ+ patients and caregivers may perceive disclosure as risky (Candrian and Cloyes, 2020) and avoid disclosure if they are concerned that they or their caregiver will experience discrimination and mistreatment (Brooks et al., 2018). LGBTQ+ patients and caregivers have also described the additional cognitive and emotional burden that this risk/benefit calculus places on patients and caregivers at times when they are particularly vulnerable (Cloyes et al., 2018; Maingi et al., 2018). Moreover, some patients (such as people with dementia, as represented in Table 2, or those who are “outed” by family members or others) may not be in a position to make a deliberate choice. A recent survey of 865 hospice and palliative care providers suggests that these concerns are well-founded, as more than half of providers believed that LGBTQ+ patients were likely to experience discrimination and more than 20% had observed discriminatory care (Stein et al., 2020).

Multiple LGBTQ+ health researchers and advocacy groups have called for incorporating routine collection of SOGI and related data across healthcare settings as an inclusive standard of practice (Candrian et al., 2021). If the collection of SOGI data were normalized and routinized at intake, patients and caregivers would still have the choice of how to respond, ideally before HCT providers enter their homes. SOGI information should be one element among others collected in a multidimensional history for all hospice patients (Acquaviva, 2017).

Balancing ethics of “equal” treatment with patient-centered care

Only participants at one site (NE) received formal LGBTQ+ focused training provided by their employing hospice agency. This training was generally helpful for understanding the larger context of historical and structural discrimination and fostering empathy (Morris et al., 2019) but more emphasis on connecting these insights with specific EOL considerations is needed. Only a few HCT providers in each focus group discussed how, in addition to personal values and preferences for care, historical and structural factors also shape the EOL experiences of LGBTQ+ patients and caregivers; fewer connected these factors to their own assumptions and practices as providers. Ongoing cultural competency training for HCT providers should be required and should extend beyond “LGBTQ+ 101” to emphasize the role of implicit bias in shaping EOL care experiences of LGBTQ+ individuals and families and the conceptual and practical differences between equal and equitable EOL and hospice care.

Of note, 69% of our participants reported being religious. In our prior study of HCT provider attitudes toward LGBTQ+ hospice patients and caregivers (Cloyes et al., 2020), religious affiliation was associated with more negative attitudes while higher education and longer time employed in hospice were associated with more positive attitudes. Since many hospice agencies are affiliated with religious organizations, particularly in underserved areas, the role of religious beliefs in shaping HCT providers’ values regarding inclusive and ethical care should also be a focus (Fang et al., 2016; Acquaviva, 2017).

Opportunities to adopt and practice new ideas, language, and techniques

Participants expressed concerns about lacking the knowledge and confidence to provide care for transgender and gender-diverse patients, including lack of familiarity and discomfort with newer and unfamiliar terms and what was seen as a recent proliferation of identities. We did not note between-site differences in the statements about non-binary gender identities as being “new” or “confusing,” which may reflect broader generational differences given the average age and age range of the participants. Some participants, particularly those in the NE and SE sites, were also concerned about saying or doing the “wrong thing” when interacting with LGBTQ+ patients and caregivers. Underlying these concerns was a sense that both the home setting and the often-intimate nature of EOL care may increase the potential negative impact of mistakes. The HCT providers we spoke with prided themselves on their skilled practice in fostering a sense of safety for patients and caregivers by building trust and connection; cross-cultural situations that raise discomfort may challenge confidence and create barriers for providers to fully engage with cultural competency initiatives (Boucher and Johnson, 2020).

Despite this, a number of the providers in our focus groups wanted more education and training to learn specific and concrete communication strategies to increase their competency in LGBTQ+ inclusive care. Competency training should normalize the fact that inclusive care is not “mastered” but requires ongoing learning, practice, and reflection. Training can create spaces where HCT providers feel safe to ask questions, practice, make mistakes and rehearse inclusive vocabulary, assessment techniques, and interactions in lower-stakes settings. Active learning methods like intentional dialogue with LGBTQ+ patients and caregivers, simulations designed with LGBTQ+ community stakeholders, and improvising scenarios with feedback are promising approaches.

Study strengths and limitations

To the best of our knowledge, this is the first study to employ focus groups to directly assess hospice providers’ knowledge, experience, and opinions regarding LGBTQ+ patients and caregivers. Conducting focus groups in three different hospice agencies in distinct regions of the US was also a strength. The relative lack of racial and ethnic diversity in our sample presents a definite limitation. Also, future research should seek and integrate the insight and experiences of LGBTQ+ hospice patients and caregivers in addition to provider perspectives. Comparing these will help delineate disconnects that compromise patient and caregiver experiences and outcomes as well as positive and effective practices that enhance communication and care, as these could be supported and scaled.

Conclusion

HCT providers EOL care and support at a significant and vulnerable time of patients’ and caregivers’ lives, often within their homes. HCT providers must therefore be skilled communicators and possess the knowledge and skills necessary to provide inclusive and equitable EOL care. Providing nonverbal opportunities for all hospice patients to self-report SOGI information and required, ongoing competency training, emphasis on how contextual factors shape EOL experiences for LGBTQ+ patients and caregivers, fostering critical reflection on providers’ implicit biases, and providing opportunities to actively practice communication techniques outside of patients’ and caregivers’ homes.

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