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Social Work Practice with LGBT Elders at End of Life: Developing Practice Evaluation and Clinical Skills Through a Cultural Perspective

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This article focuses on culturally sensitive clinical issues related to best practices with lesbian, gay, bisexual, transgender (LGBT) elder patients at end-of-life (EOL) at key points in the therapeutic relationship. Vital concepts, including practice evaluation and clinical skills, are presented through a cultural and oncology lens. There is a paucity of LGBT research and literature as well as a shortfall of MSW graduate school education specific to social work palliative and end-of-life care (PELC) practice with LGBT elders. The content of this article is designed to be adapted and used as an educational tool for institutions, agencies, graduate programs, medical professions, social work, and students. Learning the unique elements of LGBT cultural history and their implications on EOL care can improve social work practice. This article provides an examination from assessment and engagement basics to advance care planning incorporating specific LGBT EOL issues.

KEYWORDS *assessment, culture, education & training, engagement, LGBT elders, palliative and end-of-life care, practice evaluation*

My review of social work research revealed a significant gap addressing the unique needs of elder lesbian, gay, bisexual, and transgender (LGBT) people with regard to social work palliative and end-of-life care (PELC) practice. Also lacking was recognition of the distinct cultural history of the LGBT community that must be understood within the context of end-of-life care

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(EOLC) in order to serve this population effectively. This article addresses key concepts of work with LGBT elder patients and families, including cultural understanding and EOL practice implications that will enhance social work service delivery. Stemming from my goals as a Leadership Fellow in the Zelda Foster Program, an aim of the article is to encourage a dialogue among practitioners and academicians that will help augment social work education, encourage institutional and direct practice evaluation, and guide the development of clinical best practices for working with this population.

LITERATURE REVIEW

Social workers are trained to use a systems-based, ecological model of practice to approach patients within the context of their environment and culture, “starting where the patient is.” Understanding the impact of cultural and community influences on EOLC for the LGBT population will help create a safe and supportive environment in which to confront matters of death and dying (Smolinski & Colón, 2006).

Counseling LGBT patients while helping them prepare for a “good and respectful death” is enhanced by understanding their unique issues relative to EOLC and initiating a culturally appropriate discussion in a nonjudgmental manner (Farber, Egnew, & Farber, 2004, pp. 102–103; Neville & Henrickson, as cited by Smolinski & Colón, 2011, p. 381; Nuland, 1995, p. 266). End-of-life care for LGBT individuals is affected by such long-standing issues as stigma, prejudice, and active discrimination that can cause undue distress and suffering. Practitioners who broaden their own sensitivity and awareness and adapt their clinical skills to provide the level of care LGBT patients deserve will preserve dignity and prevent isolation for this special population.

Little attention has been paid in the literature and research on the outcomes that stem from the lack of appreciation for, and understanding of, LGBT culture and its history of oppression. This gap manifests itself in the context of medical care, provider education, access to nondiscriminatory health care institutions, and cultural competence.

Medical Context

LGBT elders have been categorized as “the most invisible of an already invisible minority” (Blando, 2001, p. 87). For many reasons, including discrimination and internalized homophobia, older LGBT adults often refrain from disclosing their sexual orientation or are not forthcoming about the issues they face because of their sexual identity (Addis, Davies, Greene, MacBride-Stewart, & Shepherd, 2009; Blando, 2001). Many older LGBT people are distrustful and are reluctant to seek out care for themselves or to be out to their providers (Clark, Landers, & Linde, 2001). Being hesitant

to reveal their sexual identity often occurs due to previous less-than-favorable health care encounters and the diminished degree of affirmation providers and institutions have demonstrated (de Vries, 2005; Ramchand & Fox, 2008; Rutledge, Siebert, Siebert, & Chonody, 2012). The LGBT population is at increased risk for isolation from LGBT service providers, including social workers, because many service providers do not self-identify as LGBT nor do they address the corresponding medical and EOL needs of the population (Cahill, South, & Spade, 2000).

Education

Rogers, Rebbe, Gardella, Worlein, and Chamberlin (2013) spoke to the focused need for ongoing education of service providers regarding the distinctive concerns and issues of older LGBT adults, particularly at EOL. Social workers are graduating with little knowledge and few clinical skills for culturally competent practice with the LGBT population (Camilleri & Ryan, 2006; Longres & Fredriksen, 2000; Messinger, 2006; Van Den Bergh & Crisp, 2004). In Logie, Bridge, and Bridge's (2007) study of 173 MSW students, 50% reported not feeling well prepared to serve LGBT individuals and their families. Additionally, social workers who had LGBT practice experience and education were more likely to learn a patient's sexual orientation and care needs and consequently to provide a competent and focused level of care (Mustanski, as cited in Paul, 2013). In 2010 there were an estimated 2 to 7 million older (60+) Americans who identified as LGBT; this was expected to double by the year 2030 (Hospice Foundation of America, 2010). This growing subset will increasingly need services that cater to their distinct cultural issues and service needs; this will be especially the case at all levels of health care and at EOL (Beeler, Rawls, Herdt, & Cohler, 1999; LGBT Movement Advancement Project [MAP] & Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders [SAGE], 2010).

Health Care Implications

No one should have to worry about receiving discriminatory or otherwise second-rate care based on being LGBT. Yet many LGBT Americans share this concern when considering their health care, further exacerbating their overall health status (Snowdon, 2013). Of 4,916 people in the study *When Health Care Isn't Caring* (Lambda Legal, 2010), 73% of transgender respondents and 29% of LGB people reported being concerned about inappropriate, discriminatory care. Even worse, 52% of transgender respondents and 9% of LGB respondents reported "that they believed they would actually be refused medical services because they are LGBT" (Lambda Legal, 2010, p. 4).

The Institute of Medicine (1999, 2009, 2011) highlighted the need for *cultural competency*. Culturally competent practitioners approach LGBT

health care with a contextual appreciation and understanding of LGBT culture, incorporating LGBT history, stigma, laws and policies, demographics, barriers to care, and previous negative experiences with providers. Stein and Bonuck (2001) studied gay and lesbian preferences concerning the importance of patient-provider communication regarding approaches to EOL care, including advance care planning, surrogate decision making, and views on physician-assisted suicide and euthanasia.

The National Association of Social Workers (NASW) spoke clearly about the need for cultural competence in 2000 and 2001. The association stated that social workers should advocate for and participate in educational and training programs that help advance cultural competence within the profession and use appropriate clinical approaches, skills, and techniques that suggest an understanding of the function of culture in the therapeutic process. Social workers are expected to develop from “cultural awareness to cultural sensitivity” before attaining a culturally competent practice (NASW, 2001, p. 17). However, sensitivity or tolerance does not equate to competence (Logie et al., 2007).

LGBT and Oncology

According to The LGBT Cancer Project (2007), LGBT people seek care for their cancer at a later stage than heterosexuals, resulting in less information about their illnesses and psychosocial needs. Moreover, there are higher risks for certain cancers—such as Hodgkin and non-Hodgkin lymphoma; cervical and breast cancer; Kaposi sarcoma; and anal, lung, and liver cancers—among LGBT people (Burkhalter et al., 2011; The LGBT Cancer Project, 2007). Transsexual and transgendered individuals receiving hormone therapy face increased risks associated with certain cancers and treatment protocols. Appropriate cancer screening with culturally knowledgeable health care providers is vital to effective prevention, detection, and positive outcomes for this population (Center for Excellence for Transgender Health, 2011; Coleman et al., 2012). The overall impact is different from heterosexual cancer survivors particularly related to quality of life and EOL issues (Engels et al., 2008; Gay & Lesbian Medical Association, 2006; National LGBT Cancer Network, 2013).

PRACTICE IMPLICATIONS

“We don’t see things as they are, we see them as we are.” (Anais Nin, 1961)

The National Resource Center on LGBT Aging (2013) addressed statements often heard from practitioners, such as “We treat everyone as equals, so we don’t need to ask clients about sexual orientation or gender identity”

(p. 9). This sentiment can lead to a minimization of unique challenges faced by older LGBT adults, rendering everyone being treated as if heterosexual and nontransgender. Other topics addressed were “We don’t have any LGBT older adult clients” or “I can identify the LGBT people within my service population” (p. 8). Service providers should always work from the premise that they have—or will eventually have—LGBT patients, even if no one has openly identified as LGBT. Elders are particularly adept at “passing” as heterosexual or nontransgender and have been for most of their lives (p. 8).

Social workers are trained to think and operate under the distinct bio-psycho-social-spiritual model. Under this model social workers work with patients and their families through an awareness and sensitivity to their culture and to the significance of their culture in relation to their presenting issue(s). Social workers are taught about the importance of assessing a patient’s ecological factors in order to establish the adequacy and strengths of relevant systems in the patient’s environment that may directly impact healthy outcomes. Available resources often relate directly to one’s culture.

From a best practice perspective, it is important to address specific LGBT elder EOL issues utilizing specific social work cultural, assessment, and engagement principles. Implementing and understanding these principles and their direct impact on care generally leads to an effective practice and better service outcomes for this population.

Culture

Social workers are taught to understand basic cultural norms and means of expression, differentiating individual and culturally determined patterns. They are instructed to identify any cultural barriers to, or influences on, treatment outcomes, and to seek out institutional and community cultural resources, supports, and organizations in support of their patients. What they are *not* taught well is how an LGBT elder patient’s unique culture can greatly influence his/her views regarding EOL and EOLC.

CULTURAL COMPETENCE

Kaplan stated that “attending to needs along the continuum of illness, coming to terms with EOL issues, making informed decisions and ensuring society honors them, are vital life tasks” and that social work’s values and skills can make a significant contribution (Kaplan, as cited in NASW, 2014, Definitions 1. End of Life Care, para. 4). Social workers have unique, in-depth knowledge of, and expertise in, working with ethnic and cultural diversity; family and support networks; interdisciplinary practice; interventions across the life cycle; and systems interventions that address the fragmentation, gaps, and insufficiency in health care. “When confronting issues related to palliative and end of life care, social workers have a multidimensional role as

clinicians, educators, researchers, advocates, and community leaders” (NASW, 2004, p. 14).

The term cultural competence integrates various terminologies, including cultural awareness and humility, and skill building, in relation to LGBT culture (Clark, 2013). Competence also requires one to be self-reflective and aware of one’s own personal and cultural beliefs and values about LGBT issues. Cross-cultural leadership, communicating to and educating other disciplines, is an essential aspect of an oncology social worker, especially when working as a member of an interdisciplinary team.

LGBT CULTURE

Although individual lesbian, gay, bisexual, and transgender populations often are combined as a single entity for research and advocacy purposes, it should be understood that each is a distinct, subcultural group with its own specific needs. LGBT diversity exists across many domains: gender, age, race, ethnicity, social class, LGBT identity, geographic location, beliefs, behaviors, and attitudes (SAGE, 2013). Of particular note, the domains of age and geographic location stand out. An older LGBT person, versus one from a younger generation, may be heard to say: “I feel different from younger gays. They live in a different world than we did.” “I feel judged by the ‘queer movement.’ In my day, you had to hide and be secretive” (Council on Social Work Education [CSWE], 2009, Slide 9). This sense of difference between old and young can lead to elder shame—feelings of shame for acting and behaving due to their generation’s general life experience.

Geographically, the difference between rural and urban settings is a significant variable that affects EOLC. In small, rural towns, patients who are able to access local services often choose not to in order to protect their privacy and identity; some travel to obtain services, others do without. In rural communities without a visible LGBT presence, connections to other rural LGBT people for support, levels of *outness*, importance of LGBT identity, and lower income levels can have significant ramifications for EOLC. They particularly do not have access to advance care planning and quality EOLC when it is most needed (Cartwright, Hughes, & Lienert, 2012). There may be institutional and community resources, local and national help (e.g., local LGBT community centers, National Resource Center on LGBT Aging, and Human Rights Campaign) available, including other patients who may be willing to meet and share experiences. Facilitating referrals to Internet resources for legal information, national and international LGBT sites, and social support sites may help to connect this population (e.g., Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders), particularly in rural communities. Whether the nearest LGBT resource is near or hundreds of miles away, social workers can establish contact so that appropriate referrals can be made—even if only by phone or Internet.

The history of discrimination and multiple losses is also a significant cultural determinant with regard to stress and suffering that distinguish this culture from the mainstream when it comes to EOLC. Transgender patients are even more likely than LGB patients to face discrimination, in part because they are less able to hide their difference. LGBT people have also encountered more personal and cultural losses than the mainstream culture due to tremendous losses of life from the HIV/AIDS epidemic and the loss of familial relationships due to rejection based on one's sexuality or gender identity (Appleby & Anastas, 1998).

LGBT people have been targeted and victimized. According to state-level, population-based studies and a national community-based survey of over 2,560 LGBT older adults, Fredriksen-Goldsen et al. (2011) stated that the most common types of victimization were verbal insults (68%), threats of physical violence (43%), and police harassment (27%). Nearly 66% of LGBT elders had been victimized three or more times over the course of their lives (CSWE, 2009). They grew up in more extensively oppressive and homophobic eras when homosexuality was viewed as criminal and as a mental illness. Many did not see themselves as worthy of basic entitlements—hence they did not seek assistance easily and therefore did not often seek out help with EOLC planning. They have been referred to as the “closeted population”—in order to survive they became experts at hiding their identities and relationships—socialized to hide. Often, they do not use the labels lesbian or gay to define themselves. “We identify simply as two women living together in a primary relationship,” said one 75-year-old who had been partnered for 41 years. “This is not just being closeted; it is not having words to name oneself” (CSWE, 2009, Slide 12). If out, they have often lost their employment, their apartments, been discharged from the military, and renounced by their families. Dr. Melinda Lantz said, “There is something special about having to hide this part of your identity at a time when your entire identity is threatened. That's a faster pathway to depression, failure to thrive and even premature death” (quoted in Gross, 2007, para. 16).

CULTURAL IMPACT ON HEALTH CARE

In 2011, of 2,560 diverse LGBT older adults age 50 to 95, from 11 community-based aging agencies across the country, 13% report having been denied health care or provided substandard care, with 4% having had this experience three to four times over the course of their lives; lesbians (11%), bisexual women (11%), gay men (11%), bisexual men (11%), and transgender older adults (40%). Inclusively, 15% feared accessing care outside the LGBT community; interestingly, 8% feared accessing care within the community; and 21% of LGBT older adults had not disclosed their orientation to their medical providers (Fredriksen-Goldsen et al., 2011).

Cook-Daniels and Munson's (2010) surveys found shame and fear to be the leading contributors to why this elder population does not access services when most needed.

There are an estimated one million LGBT cancer survivors (Livestrong Foundation, 2010, p. 1). Compared to their heterosexual equivalents, LGBT people are two times as likely to live as a single person, two times as likely to live alone, three to four times less likely to have children to support them, and five times less likely to access aging services. One often hears an LGBT elder say, "We take care of our own without outside help" (National Resource Center on LGBT Aging, 2011a, video).

Social workers may be the only team members taking the time to assess and invest in the EOL experiences of LGBT elders, providing a safe environment for them to vocalize their needs and wishes for their end of life experience so they feel less disenfranchised and find their EOLC "voice" (Smolinski & Colón, 2006, p. 61). LGBT patients may have a particularly difficult time coping with stress at EOLC if the systems that are providing their care are insensitive, discriminatory, or punitive. If, however, the care is sensitive, the EOLC may overcome the lifelong struggles related to homophobia, including external and internalized oppression.

Assessment

CULTURAL ASSESSMENT

It is important for social workers to assess and understand the connection between the patient's culture and any EOLC issues he/she presents. Exploring the relationship between his/her presenting issue and past cultural life experiences is essential. As Stein, Beckerman, and Sherman (2010) stated, there are crucial common denominators in LGBT EOLC to take into account when assessing a patient's cultural experiences: Fears of Isolation, Neglect & Safety, Emotional/Physical Abuse, Lack of Acceptance & Respect, Forced to Return to the Closet, Inhibited Intimacy/Sexuality, Fear of Unequal Health Care Treatment, and any Complicated Legal & Financial Matters (pp. 427–428).

A social worker could ask the following questions, for example:

- From a cultural standpoint, how does this [insert EOL issue] affect you and your loved ones?
- Is there a relationship between the issue(s) and your LGBT cultural history?
- Do your friends and family see the issue as you do, or do they see it differently?

There can be differing cultural viewpoints among family, friends, and patient, depending on their relationship to the various denominators.

INSTITUTIONAL/CENTER ASSESSMENT

In addition to evaluating the LGBT patient's culture, the institution or center can be assessed. The social worker can ask these questions:

- Are LGBT patients coming to the center?
- How LGBT-friendly is the institution?
- Is this institution a safe and supportive environment in which to discuss EOLC?

For example, has a social worker, as one might for another population, walked through, observing the center from a particular LGBT cultural perspective, taking into consideration the structural elements with regard to the physical space, patient flow, and safety (Wilkerson, Rybicki, Barber, & Smolenski, 2011)? These elements include visual cues, restroom designations, clinical mission statement, policies, and forms. Social workers will want to include their personal space where they see patients when they are assessing the above environmental areas: How might an LGBT person assess whether or not I and my space are safe? Am I the “*safe one*” in what might be an otherwise perceived unwelcoming environment (Smolinski & Colón, 2006, p. 61)?

LGBT ASSESSMENT GUIDE

It is vital that a social worker conduct an appropriate assessment in order to ascertain information crucial in providing a proper level of care, addressing all EOLC needs. Understanding the impact of heterosexism and homophobia is essential for effective EOL assessments, interventions, and knowledge building. The following assessment fundamentals can act as a guide to inform one's practice (Appleby & Anastas, 1998; Potter, Goldhammer, & Makadon, 2008):

- Is it the default to assume all patients are heterosexual?
Never assume a patient is heterosexual or homosexual.
- Be aware of personal feelings/thoughts and consequent countertransference.
With most people having been brought up in a society that privileges heterosexuality, it is important to understand that the predisposition this introduces is not automatically lost because one is a social worker (Clark, 2013).
- Recognize that not all issues a patient has are associated with being LGBT or having cancer.
Be sure to assess differentially.
- Comorbidities of cancer and HIV/AIDS, both stigmatized illnesses, come with their own psychosocial needs in relation to LGBT EOLC.
Be sure to assess for potential areas of need due to each illness.

- When sexual orientation or gender identity is unknown, a social worker's attitude and language, if not expressing openness, can be actively, if unwittingly, painful and alienating to the patient.
- Acknowledge the patient's social identity by exploring sexual preferences and acknowledging transgender oppression—sexism, heterosexism, transphobia, and transprejudice.
- Use the same language the patient uses.
 - Ask about her/his support system rather than children, or about her/his partner rather than spouse, adopting open-ended, gender-neutral questions about supportive relationships and next of kin.
- Ask whether patient holds beliefs that are prevalent within the LGBT culture involving EOLC.
- Do not assume LGBT patients know about LGBT services and EOLC issues just because they are LGBT.

INCLUSIVE DISCLOSURE QUESTIONS

Smolinski and Colón (2006) stated that LGBT couples, for example, cannot be appropriately supported if the relationship is not known. The following disclosure questions may be of use in helping LGBT patients engage and to feel comfortable building a strong therapeutic alliance, sensing that they are not being asked heterosexist/noninclusive, assumptive questions:

If patient's LGBT status is unknown:

- Do you live with anyone? What is his/her relationship to you?
- Are you in a relationship with someone you do not live with?
- Who is most likely to visit you while you are in the hospital?
- Is there someone you would like to include in the decisions about your care?
- Do you have a spouse/partner/significant other? Are you in a romantic relationship?
- Are there those whom you consider your family, but who are not biologically related?
- Who are your most important support people?

If the patient is open about himself/herself:

- How open are you? Does your family know that you are LGB or T?
- Do you have the support of friends and family?
- Does your partner communicate with your family and siblings?
- How would you like staff to address your partner and how would you like to document this information in your chart?
- If patient has a partner/spouse/caregiver, is that person "out" or "in"?

(Cisneros & Dikeman, 2013; Neville & Henrickson, as cited by Smolinski & Colón, 2011, p. 381; Røndahl, Innala, & Carlson, 2006; Smolinski & Colón, 2006).

Specific LGBT End-of-Life Issues

LEGAL CONCERNS

It is often necessary to refer LGBT patients for legal assistance. Many have unique legal and financial concerns and require expert guidance. Social workers can reach out to the local legal community for LGBT expertise, or they can seek out contacts in their own or neighboring states and nationally to provide in-person or phone consultations, perhaps through a monthly clinic or educational offering.

LONG-TERM CARE AND SKILLED NURSING FACILITIES

Without traditional support systems in place, many LGBT elders end up relying on nursing homes or other institutions providing long-term care (LTC). Unfortunately, these institutions are typically heterocentric and gender-normative in construct. According to a survey by the National Senior Citizens Law Center (NSCLC, 2010), only 22% of LGBT seniors and 16% of non-LGBT respondents (combined $n = 744$) answered that LGBT seniors can feel safe being open about their sexual orientation in LTC facilities. Among comments received in the survey, a 73-year-old male, soon to be an LTC resident, stated, “Due to my financial situation, I will have to share a room with another man. The thought of going back into a closet is making me ill. Frankly, I’m afraid of telling anyone that I’m gay” (p. 6). Also from the survey, an 83-year-old skilled nursing facility (SNF) resident asked, “Will the aide be ‘comfortable’ helping a gay male bathe?” (p. 14). “Depending on someone for bathing, toileting, and feeding who deeply disapproves of who you are can be an extremely stressful experience” (p. 14).

Cahill, Ellen, and Tobias (2002) discussed how LGBT patients were reluctant and often outright refused to have “strangers” (home care providers) in the house, afraid that the provider would discover they were LGBT. Those seniors were concerned about providers coming into their homes and seeing their pictures and their personal environment. They worried that a provider might be sent to their house and they would not know how to react—closeted or not.

- Will the provider tell my family, coworkers, and/or faith community that I am LGBT?
- Will they reject me?
- Will they hurt or abuse me?
- Will I get the care I need and the dignity I deserve? (Cahill et al., 2002)

In addition, several respondents in the NSCLC (2010) survey reported being “prayed over” or being told that they would “go to hell” for their sexual orientation or gender identity (p. 11). Many hospice organizations, home care services, and inpatient/outpatient services have religious underpinnings that could make for a difficult EOL transition for LGBT patients and their loved ones. It is important to know, as best one can, the level of LGBT cultural preparedness, openness, and inclusivity of the LTCs and SNFs to which referrals are regularly made. Of 769 individuals who completed the NSCLC survey on LGBT elders in LTCs and SNFs, respondents predicted abuse or neglect by staff 53% of the time, isolation from other residents 77%, discrimination by residents 81%, and discrimination by staff 89% of the time. Patients stated that staff refused to refer to transgender residents by preferred name or pronoun, refused to accept power of attorney (POA) and/or health care proxy (HCP) from a resident’s spouse/partner, refused to provide basic services or care, imposed restriction of visitors, and, in some cases, denied medical treatment.

END-OF-LIFE WISHES AND ADVANCE CARE PLANNING

It is especially important for LGBT older adults to consider EOL wishes and advance care planning, including advance directives. (The documents may have specific or slightly different nomenclature by state.) EOL wishes include managing one’s fiscal responsibilities (e.g., POA), permanency planning, final arrangements, hospital visitation, and drafting a will. Not all states include LGBT partners in their inheritance laws—as all states do for married couples—so being sure to specify the beneficiaries ahead of time becomes all the more important. This planning includes such areas as a person’s IRAs, 401Ks, 403Bs (including rollovers and distributions), and other retirement or pension plans. Children’s health insurance is also of concern, depending on the tax implications and based on parental legal status, biological or adoptive (Lambda Legal, n.d.; National Resource Center on LGBT Aging, 2011b).

Advance directives cover items such as a living will, a health care proxy, medical orders for life-sustaining treatment, and the disposition of one’s remains. Exploring these and related topics with their social workers may mitigate discrimination and inappropriate care, particularly ensuring that same-sex partners and other members of families of choice are involved in EOLC and decision making (Cartwright et al., 2012). Auger (2003) concluded that closeted and rural gay and lesbian couples deliberately did not engage in EOL planning in order to maintain privacy. Bullock (2011) noted that when practitioners have a keen awareness of the subtleties involved in successful EOL wishes and advance care planning related to culture and family dynamics, they provide care “infused with dignity and respect and consistent with patient and family wishes” (p. 625). Nonetheless, some LGBT elders resist all efforts to engage them in EOL planning. Having struggled throughout life

due to discrimination and having fought so hard against HIV/AIDS and physical abuse, they are determined to resist death and to deny its possibility with regard to them.

HOSPITAL VISITATION DIRECTIVE

This directive specifies whom a patient wants to have visit—or not visit—while she/he is in the hospital. President Obama's Memorandum on Hospital Visitation directed the Department of Health and Human Services to initiate rulemaking to ensure that hospitals receiving Medicare or Medicaid payments respect the rights of patients to designate visitors, regardless of sexual orientation, gender identity, or any other nonclinical factor (White House, 2010). Complete this form in advance; a patient may not be able to designate his/her preference once in the hospital.

LAST WILL AND TESTAMENT

A will is a legal document that indicates how one's estate will be managed and distributed after their death. LGBT patients may have estranged family members who, without the presence of a will, may have the right to take what they want from the estate. This is a state-by-state matter and legal counsel is advised.

HEALTH CARE PROXY

The health care proxy (HCP) allows people to designate an agent to execute decisions about their health care—including decisions about life-sustaining treatment—if they can no longer speak for themselves. A detailed conversation between the patient and his/her agent can clarify what decisions he/she would like made. This document is especially important to LGBT people: if a proxy has not been previously designated, hospitals and courts can seek out biological family members to make health care decisions (Human Rights Campaign, 2015).

LIVING WILL

In the event someone cannot make her or his own health care decisions, this document speaks to that person's wishes regarding multiple levels of care. It also allows someone to arrange for organ donation, levels of pain relief, funeral, and other advance planning wishes. Like the HCP, it is vital that LGBT people have a living will prepared in order to ensure their wishes be respected and not have health care decisions made by the courts and/or unchosen biological family members (Human Rights Campaign, 2015).

PERMANENCY PLANNING

Who will care for a patient's children? Families headed by a same-sex couple are particularly vulnerable when one member of the couple dies. This is especially the case when a family has children and lives in a state where neither joint nor second parent adoptions are legal options. Permanency planning allows for the designation of a guardian over one's children (National Resource Center on LGBT Aging, 2010).

FINAL ARRANGEMENTS (ALSO KNOWN AS A FUNERAL DIRECTIVE)

Who will carry out the patient's wishes, have authority over the remains, and make funeral-related decisions? Are there wishes about a particular funeral home, cemetery, headstone words, and maintenance of the plot; is there some alternative way that the patient wishes to be remembered in the future? There have been numerous cases where a cemetery has refused to add the words "life partner" because of homophobia. If the patient has a spouse or life partner, how is that person to be described in the obituary—"survived by"? How would the patient's gender identity be described? Does the patient want any religious content at the funeral/memorial? Does the patient have any specific wishes for how they want to be described (Lambda Legal, 2010)?

DISPOSITION OF REMAINS

This document provides for the designation of an agent who shall have the right to control the disposition of the remains of a deceased person. Most states allow legal relatives to make decisions related to the deceased's body, including funeral arrangements. An agent is important if a person anticipates a dispute among his/her survivors (especially estranged family members). It takes on even more importance when the person does not have family who will be seeing to the arrangements, especially if the person wishes to be cremated (New York State Department of Health, 2006).

It is important for LGBT patients to communicate their wishes to partners, family, and health professionals before they become incapacitated. If they do not, they risk having their wishes and those of their close friends and partners overridden by biological family members and health care workers who may not execute the patient's dying wishes. When advance care planning concerning health care and finances is well organized and appropriately communicated, it is possible for LGBT patients to experience proper EOLC and to die with dignity.

RELIGION AND SPIRITUALITY

Exploring religion and spirituality is important to a comprehensive assessment, especially as it may serve as a foundational strength for the LGBT elder. In a survey of 2,560 LGBT elders, 38% of respondents

attended spiritual/religious services or activities at least once a month (Fredriksen-Goldsen et al., 2011). Bozard and Sanders (2011) stated that many patients facing EOL derive comfort from their religious/spiritual beliefs. However, religious concerns can also be a source of pain and spiritual distress; for example, if a patient feels punished, judged, shamed, or abandoned by God for being LGBT. According to Kellems and Fassinger (2003), LGBT persons looking to incorporate religious or spiritual coping into their lives often struggle in their attempts to uphold, adapt, or discard religious doctrine and spiritual beliefs discordant with their sexual orientation, facing personal struggles related to faith and identity.

Many LGBT people at EOL struggle with existential distress and suffering, such as experiencing a sense of being alone and isolated in the world, believing that one's life has or has had no meaning or purpose and feeling distress from not having continued the family line through reproduction, not leaving offspring to be remembered by (James, 2008). In addition to a standard religious/spirituality assessment, it is important to inquire as to the LGBT patient's history with religion/spirituality and any significant events particularly related to sexual and gender identity. How does the patient currently feel about religion in her/his life?

SEXUALITY AND INTIMACY

Redelman (2008) stated that "If touching and hugging cannot be open . . . , then extra pain is suffered" (p. 369). Meyer stated that of 3,000 LGBT respondents, 50% of people aged 65–74 remained sexually active and 54% of people age 75–84 say they had sex 2–3 times a month, and that many providers reported high levels of discomfort taking the sexual history of LGBT patients (Meyer, as cited in Davis, 2013). In a qualitative study (Lurie, 2005), 13 HIV providers conveyed their discomfort in asking sexually focused questions as one of the most imposing issues with regard to their treatment and care of transgender patients. For many LGBT patients/couples, sexuality and intimacy do not have to end because one is approaching EOL, though it can be culturally and institutionally inhibited. An important part of comprehensive EOLC is to engage individuals/couples in a conversation about different levels of intimacy, including their sex life, while taking into account cultural and institutional inhibitions. A social worker can ask, "How has the level of intimacy been for you both? Have you felt comfortable expressing yourselves here at the Center, in the LTC/SNF/Hospice, or at home in front of your health care worker?" For some individuals who are single, exploration may require conversations involving their particular sexual interests—Internet, sex workers, etc. This may open up a conversation that allows an exploration of options and to confront inappropriate attitudes and behaviors. It is a unique dynamic for both individuals and couples and it is important to find a personalized solution.

CAREGIVERS

“Family Caregivers” refers to all people who provide or manage the care of someone who is chronically or seriously ill. LGBT caregiver identity may be kept private as some choose the path of less resistance and go along with any misunderstanding for fear of harassment and inadequate care (SAGE, 2011). LGBT persons might have primary caregivers who are close friends, relatives, or partners who live separately. Not frequently seen or accepted as support, and often hidden, ex-lovers accounted for 16% of support teams in a study of over 300 LGBT cancer survivors (Margolies, 2013). Family caregivers may be part of the patient’s family of origin or family of choice. Midlife and older gay men and lesbians have often experienced multiple losses and chronic bereavement particularly due to the HIV/AIDS epidemic (IOM, 2011). The LGBT caregiver may be caring for a partner, an LGBT friend, and a parent all at the same time often leading to caregiver burnout. LGBT elders are more likely to be single, childless, estranged from their biological family, and reliant on families of choice, such as friends and other loved ones. Without traditional support systems in place, many LGBT elders end up relying on nursing homes or other institutions providing long-term care (LGBT Movement Advancement Project [MAP] & SAGE 2010). “As strong as I am today,” a patient said, “when I’m at the gate of the nursing home, the closet door is going to slam shut behind me” (Gross, 2007, para. 35).

When you put that together—the absence of adult children and a partner to help, and add barriers to accessing services, and limit the financial means others have—then this very thin network of support breaks at exactly the wrong time, right when there is an increasing need for services. (Christensen, 2012, para. 11)

DISCUSSION

Can EOLC social workers make these statements? I am prepared to advocate on behalf of my LGBT patient, I seek out educational experiences to enhance my understanding and practice effectiveness, I am knowledgeable about the issues and challenges facing LGBT elders at EOL, I feel competent in my ability to work effectively with this population (Logie et al., 2007)?

There is a clear need for more graduate school curriculum and field learning education for students, faculty, and social workers in the field involving the unique cultural impact on LGBT people and social work best practices, particularly at EOL. First is the development of LGBT practice courses, which could be offered as interdisciplinary electives. Second, a curriculum can be created that is integrated throughout the master’s program core course work (Bridge, Schenk, & Popp, 2000; Crisp, 2006; Logie et al.,

2007). This curriculum could incorporate an examination of theoretical models for their unconventional application to LGBT elder EOLC issues. The NASW (2008) Code of Ethics stated that social workers should demonstrate a working knowledge of the theoretical models essential to effectively practice with patients and professionals in EOLC. Also needed is training for other professional providers, such as nurses and doctors. A recent study revealed that one third of 132 medical schools surveyed provided zero hours of clinical training related to LGB health (Obedin-Maliver et al., 2011). There are three primary approaches to cross-cultural education: address cultural sensitivity, awareness, and approach; increase multicultural/categorical approach through knowledge; and develop an approach that fosters an increase in the patient's trust through openness and transparency (Werner, 2012). Further use and development of educational content such as the best practices presented in this article, are integral to an overall continuing social work education.

Gerontology literature is somewhat deficient regarding LGBT individuals, much less same-sex couples, and most same-sex couples research has tended to be done on a younger cohort (Dziengel, 2012). Research looking at the elderly and the differences between the boomer generation and a younger cohort is needed. Of nearly four million studies about physical health published between 1980 and 1999, only 1% reported effects for LGB participants and few of those explored health outcomes unrelated to HIV/AIDS (Boehmer, 2002). Further research and understanding about older same-sex couples and methods to support them, including addressing their specific EOLC needs, would enhance best practices (Dziengel, 2012). It is important to research this population not as a single entity, but separately from the perspective of L, G, B, & T focusing on their distinctive EOL health needs and their demographic constellation (Comerford, Henson-Stroud, Sionainn, & Wheeler, 2004).

Research for EOLC LGBT people could be enhanced utilizing data from The Veterans Health Administration (VHA) as it is likely the largest U.S. provider of health care to LGBT people (Mattocks et al., 2014). Recognizing the VHA's long history of discrimination toward the LGBT population founded in federal and military policies, much could be gained by researching the LGBT veteran health care experience. Understanding LGBT patient-provider relationships and the policies that have had a profound impact on them could lead to better understanding of the needs of this population. While the VHA has more recently created additional inclusionary policies and practices addressing both patient and caregiver needs, there still remains a severe lack of training and guidance to providers in providing culturally competent, first-rate care to the LGBT population (Mattocks et al., 2014). Further development and research into these areas: education; the distinct needs of each L, G, B, & T population; and utilizing existing and potentially quite useful data would greatly assist in developing social work best practices for LGBT elders at EOL.

CONCLUSION

With a multifaceted understanding of the distinct cultural history of LGBT elders, I challenge those working with these patients at EOL to engage in an ongoing professional dialogue focused on augmenting social work education, encouraging institution and direct practice evaluation, and guiding the development of clinical best practices for this often hidden population. The issues presented in this article, through a cultural lens, are intended to spark a new understanding of, increased advocacy for, further research into, and increased educational opportunities for social work practitioners. When confronting LGBT EOLC issues, social workers have a multidimensional role as clinicians, advocates, educators, team role models, researchers, writers, and EOLC leaders. Social workers come to the table with a unique training and skill-set foundation. That foundation, together with increased LGBT cultural training, equips social workers for the opportunities to effectively impact the end-of-life care of LGBT patients and families. Is the profession meeting these patients' needs?

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