

Special Series on Diversity

Current Best Practices for Sexual and Gender Minorities in Hospice and Palliative Care Settings



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Abstract

Although several publications document the health care disparities experienced by sexual and gender minorities (SGMs), including lesbian, gay, bisexual, and transgender (LGBT) individuals, less is known about the experiences and outcomes for SGM families and individuals in hospice and palliative care (HPC) settings. This article provides a brief overview of issues pertaining to SGMs in HPC settings, highlighting gaps in knowledge and research. Current and best practices for SGM individuals and their families in HPC settings are described, as are recommendations for improving the quality of such care. *J Pain Symptom Manage* 2018;55:1420–1427. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Sexual and gender minorities (SGMs), minority health

Experiences of Sexual and Gender Minorities in Health care Settings

Over the last decade, awareness of the bias and discrimination experienced by SGM individuals, their partners, and caregivers has increased. SGMs have been found to experience higher rates of poverty, housing insecurity, food insecurity, and workplace discrimination.¹ Research shows that SGMs have reduced access to medical care and greater levels of discrimination in health care settings than their heterosexual counterparts.^{1,2} These inequities in turn influence perceptions, attitudes, and values of SGM individuals in accessing health care.³ Several studies document high levels of mistrust of the health care system particularly among transgender, HIV-positive, and aging SGM populations.⁴ According to the landmark Institute of Medicine report,⁵ lack of education and research on the needs of SGMs, lack of cultural competency training for providers, and the absence of legal protections are key factors that contribute to the health care disparities experienced by SGMs.

SGM individuals experience higher rates of chronic conditions and higher rates of mortality from chronic medical conditions. SGM individuals are more likely than heterosexuals to rate their health as poor and to have more chronic conditions and a higher prevalence and earlier onset of disabilities.⁶ Lesbian and bisexual women also are at heightened risk for some cancers and higher rates of cardiovascular disease.⁶ Similarly, gay and bisexual men experience more cancer diagnoses and have lower survival rates, as well as higher rates of cardiovascular disease and higher number of acute and chronic conditions.⁶ Gay men have a higher risk of anal cancer and HIV-related malignancies.⁷ Lesbian women have higher lifetime risk of breast, ovarian, and cervical cancer than heterosexual women.⁸ In 2010, gay and bisexual men and other men who have sex with men who only represented an estimated 2% of the U.S. population accounted for 56% of all people living with the HIV virus and two-thirds of new infections.⁹ SGM individuals are two and a half times more likely to experience depression, anxiety, and substance use. History of discrimination and stigma contribute to these higher risks.⁶

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In the last decade, there has been a shift in the U.S. in societal attitudes toward SGMs, with a movement toward greater visibility and acceptance. This has resulted in expanded legal protections in areas such as hospital visitation rights (Presidential decree) and marriage rights (Supreme Court ruling).¹⁰ The Affordable Care Act expanded access to health insurance for SGM individuals and included specific protections related to sexual orientation and gender identity (SOGI) particularly for transgender individuals. The Supreme Court's overturning of the Defense of Marriage Act coupled with state legislation of same-sex marriage also increased access to insurance for married same-sex couples. In addition, federal regulations in effect since 2011 require hospitals that receive reimbursement from Medicare or Medicaid to have written policies and procedures that explicitly prohibit discrimination with regard to visitation based on SOGI (DHHS 2010, CMMS 2013).

The need for research on health care disparities in this population was recently emphasized with the designation of SGMs as a population with health disparities for research purposes by the National Institutes of Health and with the inclusion of SOGI data collection in some studies and some electronic medical records.¹¹

Unfortunately, in the current political climate, setbacks in access to insurance, funded research, and legal protections are likely. The current administration has already removed SOGI questions from a national aging survey and decided not to add a transgender identity field to a national disability survey as planned.¹² Most worrisome is the impact on Section 1557 civil rights protections for gender discrimination in the Affordable Care Act if this act is repealed. While protecting women in general, this clause effectively protects transgender individuals from discrimination in medical settings. The changes in the U.S. political environment are already negatively impacting the health of SGMs.

Health care disparities experienced by SGMs in other phases of life extend to chronic life-limiting illness and end-of-life care.

The factors that contribute to health care disparities experienced by SGMs that we described previously also impact patients experiencing serious and terminal illnesses. The lived experiences of SGMs, especially transgender individuals, may mean that when HPC teams operate "as usual," the quality of care received by patients and their loved ones is subpar. Most SGM patients are willing to provide information on their sexual orientation or gender identity. However, homophobia and fear of negative consequences hinder willingness to disclose this information.¹³ However, current health care practice is to place the responsibility of disclosing one's minority status on the patient who may fear of discrimination at a time when he or she feels especially vulnerable due to illness.¹⁴ This may be particularly true if the care is being provided by an organization affiliated with a religious organization. SGM patients who may have experienced shaming by religious communities may fear that disclosure of SGM status may place them at risk of discrimination by providers, or they may be suspicious of pastoral care providers and not be open to pastoral care interventions that may help lessen their psychosocial distress. Table 1 lists the potential barriers to quality HPC SGMs may experience and their potential consequences.

Existing Palliative Care and Hospice Literature on SGMs

The first U.S.-based publications on the experiences of SGMs in HPC settings appeared in the 1980s during the height of the AIDS crisis, before the introduction of antiretroviral medications.²⁴ These studies focused

Table 1

Potential Barriers to High-Quality Hospice and Palliative Care That Sexual and Gender Minorities Might Experience

Potential health care organization barriers	Potential consequences
Heterosexist assumptions of patient's sexual and gender identity ¹⁵	Lack of inclusion of families of choice in decision making ^{16,17}
Lack of provider training about caring for SGM patients ¹⁸	SGM patients' needs may not be understood, and they may experience bias from their provider (conscious or unconscious)
Lack of culturally competent caregiver support and bereavement groups ¹⁹	Higher levels of caregiver strain ¹⁸ and disenfranchised grief
Lack of integration and availability of resources for SGMs ^{16,19}	Lower levels of satisfaction with care ^{19,20}
Potential sexual and gender minority barriers	Potential consequences
Estrangement from family of origin ²¹	Incorrect assumptions in regard to surrogate decision making
Higher rates of mistrust of health care systems ²²	Delayed uptake of medical care ²¹
Nondisclosure of SGM status	Higher levels of disease-associated distress ¹⁹
Fear of discrimination by health care providers ^{15,21}	Nondisclosure of SGM status and need to distance from friends and community ²²
Complexity of relationship with religious-based organizations	Delayed access to care ²³ ; reluctance to use pastoral care resources
Isolation and lack of social support ¹⁷	Greater levels of disease-associated distress ¹⁸
Potential societal, health care insurance, and legal barriers	Potential consequences
Variability in and potential fragility of legal protections	Loss of access of SGM spouses or partners to health care insurance
Lack of comprehensive legal protections ³	Child custody not formalized; burial rights for transgender individuals not observed

on the needs of gay men as bereaved caregivers experiencing multiple losses.²⁵ They revealed unique challenges including discrimination by health care professionals and systems, estrangement from family of origin, variable levels of disclosure of SGM status to family and health care providers, a desire to preserve the role of chosen families in decision making, the difficulty of same sex partners to access loved one especially in hospitalized settings, and high levels of mistrust particularly of religious-based organizations. These studies demonstrate a clear need for inclusive and culturally competent end-of-life care, caregiver support, and bereavement services and for arranging legal protections when possible.^{15,16,26} Cartwright et al. noted that bereavement may differ markedly for SGMs and their loved ones compared with heterosexuals. This may include survivor guilt for remaining partners or disenfranchised grief, where the bereavement experienced is not acknowledged or perceived as legitimate by health care providers or others. For transgender people, lack of understanding or appropriate acknowledgment of sex identity and gender expression may cause substantial difficulty in accessing palliative care services. The authors emphasize the importance of communication and advocacy by health care providers.²⁷

In 2011, the Institute of Medicine report on the health of LGBT people⁵ provided a comprehensive update on the state of SGM health research. Although end-of-life care issues unique to SGMs are discussed in brief in its section on older adults, there is little to no mention of the unique palliative care needs of these populations. Lack of legal protections, absence of social support, and isolation from families of origin were cited as significant barriers to quality end-of-life care often experienced by SGMs. The report addressed the greater importance of addressing advance care planning for SGMs versus their heterosexual counterparts. It also mentioned some of the unique characteristics of grief for SGM persons. However, despite acknowledging that SGMs in HPC settings face unique challenges, no specific guidelines were presented that would improve the quality of care received. The report strongly recommended across all clinical and research settings 1) inclusion of SOGI variables in data collection in research databases and at the level of the clinical encounter, 2) improved cultural competency, and 3) protection from discrimination in health care settings.⁵

This report sparked further research into the barriers experienced by SGMs in HPC settings. A systematic review of existing literature highlights the need to educate health care providers to explore sexual preferences and recognize the role of partners in decision making and to refine services for these patients.²⁸ Collaborative efforts with expert panels focusing on

the needs of older lesbian, gay, bisexual, transgender, and queer individuals in hospice settings have cited similar barriers.^{29,30} One report by the national council for palliative care in the U.K. and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organizations, *Open to All?*, found that more than 70% of LGBT people thought that end-of-life care services did not use appropriate language. More than 700 of the surveyed hospices, hospitals, and care homes and their end users expressed concerns that a significant proportion of SGMs are not accessing appropriate care because of their SOGI.³¹ Heterosexist assumptions made by providers, lack of recognition of loved ones and families of choice, social and familial rejection, fear of revealing minority status, lack of legal protections, and fear of discrimination are recurring themes throughout these reports. These reports provide other insights about the experiences of SGM individuals in HPC settings. Despite existing legislative advances, the recent ACCESSCare national qualitative interview study of 40 patients with advanced illnesses not limited to HIV/AIDS highlighted ongoing experiences of discrimination and exclusion in health care.¹⁷ Owing to past rejections by certain faith-based communities,³² some SGMs distrust specific aspects of palliative medicine, such as pastoral care. Delay in accessing health care, primarily due to fear of discrimination and/or lack of insurance, may result in late referral to HPC services. Reluctance to participate in home-based care is another barrier. Elder SGMs as recipients of home-based care may feel the need to hide their sexuality or “go back in the closet” in their previously safe homes to prevent discrimination and possible abuse. The high rates of fear of disclosure among SGM elders are consistent with their lived experiences through times when medical establishments criminalized, confined, and labeled them. Finally, many SGM elders experience discrimination in long-term care and respite care settings by staff, providers, and other patients.³³

There is a lack of literature focusing on the experiences of transgender patients at the end of life.³⁰ High levels of mistrust of health care systems and providers among transgender individuals and communities are well documented⁴ and arguably justified given high levels of mistreatment and being turned away when seeking care. A study of the experiences and needs of transgender patients in relation to their concerns with end of life found that this population is not ready for events relating to end of life and has significant fears for their future.³⁰ Transgender patients in HPC settings report concerns about receiving consistent and respectful wound care that exposes the genital area after gender reassignment surgery and are very afraid that there are no legal protections in place that can prevent them from being buried under their birth gender and

name.³⁴ More recently, California has set up legal protections to help with this latter issue, but even for these patients, HPC teams are not well informed on how to help patients access these protections.

Discrimination against SGM providers and staff unfortunately occurs in the workplace, including hospitals, clinics, nursing homes, and other facilities in which SGM providers and staff work. Studies indicate stress associated to dealing with conservative and negative consequences for being “out” (openly an SGM) as a health care provider exists, including negative comments about SGMs, lack of promotions, gossips, and refusals of tenure.³⁵ SGMs working in HPC settings also experience high levels of stress and discrimination.³⁶ SGM patients may feel reassured if “out” health care providers and staff are encountered. Unfortunately, the converse may also be true.^{3,37} SGM professionals who work in health care organizations that are located in states that do not have protections in place to prevent discrimination toward SGM employees often feel disempowered from advocating for their organizations to implement policies and procedures to advance the quality of care that they provide to SGM patients. In addition, SGM physicians who work in HPC settings report experiencing discrimination in their work settings.³⁶

Gaps in Knowledge and Ongoing Discrimination

Gaps in knowledge persist owing to the relative paucity of research on the needs and experiences of SGM patients living with life-limiting illnesses. National organizations that aim to advance the quality of palliative care research do not as of yet require that core demographic data elements include items on SGM status. Adoption of a requirement to include items asking about SGM status could advance the evidence base in regard to disparities in health equity faced by SGM individuals. Although many health care organizations understand the importance of training the workforce to provide effective and equitable care to diverse patient populations, they often do not provide any in-service opportunities on caring for SGM patients,^{5,36} and undergraduate curricula have very little content on sexuality in general and little or nothing about the unique aspects of LGBT health.^{38,39} Several statements on the need to better address needs of SGMs, including those by the American College of Physicians, Institute of Medicine, American Geriatric Society,⁴⁰ and more recently the American Society of Clinical Oncology, have identified several areas of deficits in the care of SGMs that lead to health care disparities. Professional organizations such as the American Academy of Hospice and Palliative Medicine have developed strategic plans to enhance diversity and inclusion. These include specific didactic

activities at their annual meetings on topics such as implicit bias, policies ensuring equitable treatment, and promoting the development of special interest groups for minority groups such as SGM providers.

Best Practices

Despite the paucity of research on the end-of-life and palliative care experience of SGM patients and their families, international palliative care organizations and a recent U.S.-based Centers for Disease Control–funded expert panel on SGM cancer patients have proposed best practices for SGM people in HPC settings.^{37,41} These guidelines were developed by a consensus panel of 60 experts in public health, health service research, oncology, palliative medicine, SGM advocacy organization representatives, SGM health center medical providers, and SGM community members including cancer patients and survivors from throughout the U.S. The initiative was supported by a grant from the Centers for Disease Control and led by Health Link and the National LGBT Cancer Network. The experts drew on available literature and clinical and community experience to reach a consensus regarding recommendations. Recommendations were then rigorously reviewed and revised.^{37,41} Absent randomized controlled trials, these guidelines lack the levels of rigorous evaluation necessary for a traditional best practice determination. The strategy used to develop these best practice guidelines was adapted from the knowledge brokerage field where a component of the model is the synthesis of community knowledge and practice with general and specific research knowledge with the goal of translating into practical applicability. That method is built on Systematic Screening and Assessment, whose purpose is to identify, vet, and assess promising innovative programs.^{42–44}

This is a comprehensive list of recommendations:

Clinical Practice

- Collect SOGI data for all patients at initial encounters and create individualized plans with regard to disclosure or nondisclosure of SOGI to others.¹⁷
- Acknowledge that reconciliation with families of origin may or may not be welcomed or needed and should be discussed and pursued as per patients’ wishes.
- The lack of specific guidelines and standards of care for transgender patients in palliative and hospice settings should be acknowledged.³³ Patients’ wishes regarding wound care, burial rights, and when to discontinue hormones should be openly

discussed and addressed. Absent harm from hormonal medications, if the patient desires, then these medications should be continued in hospice settings. Current WPATH standards of care for transgender individuals state that hormonal therapy is contraindicated only in the presence of a thrombotic event and/or hormone-mediated cancer.⁴⁵ If it is unclear whether it is safe to continue hormonal therapy, then the patient's doctor can also be consulted.

- Address the increased risk of mental health problems and unique psychosocial barriers that exist for some SGM patients and ensure that existing quality standards for pain and symptom management are met. Include psychosocial distress, suicide risk, financial planning, and relationship with family of origin and current families of choice when performing screening and intake of SGM patients.¹⁹
- Discuss and formalize surrogate decision making during initial patient encounter, including medical proxy documentation, formalization of custody of dependent children, burial right forms, and hospital visitation forms. Recognize that it is a patient's legal right to include family of choice. These discussions must reflect changing laws and regulations and at the national, state, and institutional levels.¹⁷

Research

- Conduct research on the end-of-life/chronic illness experiences of SGM patients and their caregivers.¹⁷
- Expand research study demographic characteristics to include items on SOGI.
- Conduct research studies to better understand how the morbidity and mortality of SGM patients differs from the general population.
- National organizations that seek to promote high-quality palliative care research should require that collection of data on SOGI be considered core data elements in research studies that they fund.
- Conduct effectiveness studies into interventions that may be tailored to specific SGM patients such as use of Internet-based support and bereavement groups for SGM patients in rural and exurban areas.
- Conduct outreach with SGM persons and SGM community advocacy and support groups to solicit buy-in and gain knowledge of factors that may have impact on the feasibility of their studies and to understand their priority areas for research.

Education

- Provide ongoing training to all hospice/palliative care providers and staff to ensure culturally competent care to SGM patients and families of choice in all care settings (including hospice, long-term care, and skilled nursing facilities). This needs to include how to take a sexual history and how to identify SOGI. Provide education that addresses the mental health impact of stigmatization and discrimination.^{15,21}
- Train HPC chaplains to incorporate LGBT-specific dignity and to acknowledge potentially deleterious experiences with faith-based communities and to explore non-faith-based spirituality.²⁶
- Given the strains on social support and greater likelihood of financial stress,^{1,46} SGM patients can also be expected to have higher rates of psychosocial distress.¹⁹ In addition to proactively screening for financial distress and assistance with financial planning, train HPC social workers to understand the impact of insurance barriers to SGM individuals.
- Educate HPC clinicians to understand the variation in respect for the decision-making rights of unmarried partners at the state level. Educate HPC clinicians to proactively discuss surrogate decision making with SGM patients and the importance of designating a power of attorney for health. Train HPC staff to promote a welcoming environment for the patient's support network of choice.

Health care Organizations/Payers

- Provide in-person and/or virtual access to culturally competent and/or SGM-specific bereavement programs for SGM support networks (i.e., family of choice), recognizing the increased risk for disenfranchised grief.²⁷
- Provide ongoing mandatory in-services to all employees who interface with patients and families to facilitate their ability to provide SGM-centered care. This is particularly important for staff caring for homebound elders or residents of long-term care facilities.^{17,21}
- Give HPC workers access to tools that allow them to assess their own implicit bias in regard to groups other than their own.
- Include information in regard to resources for SGM patients and families in welcome packets, waiting areas, and examination rooms; health care organizations communicate openness to SGM patients.⁴⁵
- Make efforts to identify and honor SGM patients' preferred funeral rituals.

- Health care organizations should have statements that explicitly convey no tolerance for conversion therapy.
- Hospices need to develop explicit policies to address disenfranchised grief of surviving SGM spouses and partners. Develop relations with local SGM support and advocacy groups such as SAGE. Such partnerships can often facilitate education of SGM seniors on the importance of advanced care planning.¹⁷
- Hospitals, long-term care facilities, and hospices need to implement policies to allow them to provide effective care for transgender patients. This includes policies on how to elicit the preferred name and pronoun for the patient, as well as how to communicate that information.
- Existential grief associated with serious illness and the dying process can exacerbate internalized homophobia and transphobia. A nonjudgmental, culturally competent palliative and hospice care workforce is needed to support patients with these issues.^{17–31} Psychologists and SGM community-based resources may be helpful as well.
- Health care organizations should provide HPC clinicians with online educational resources on their intranets to facilitate effective SGM patient-centered care (see Fig. 1).
- Support policies, systems change, research, and programs that increase the availability of culturally competent palliative and hospice care for the SGM community.
- Create inclusive, safe, diverse work environments and recruit SGM minority staff and providers.³⁷
- Institutional and organizational nondiscrimination policies should include SGMs and antiharassment policies.¹⁷
- Hire SGM health care providers and staff.
- Standardized recording of SOGI should be mapped to clinical data warehouses and disease registries to permit health service research and quality improvement activities related to SGM health.

Quality of Care

- Create open-access registries with ratings of hospices' and health care organizations' cultural competence in caring for SGM patients.
- Include SOGI variables in quality-of-care metrics and consumer surveys.

Future Directions

Shifts in societal attitudes can be seen with expanded legal protections in areas such as hospital visitation rights and surrogate medical decision making. This shift can also be seen in research priorities, with the NIH's designation of SGMs as health care disparities population for research purposes and inclusion of SOGI data collection in some studies and electronic medical records.

Increased attention by professional organizations such as the American College of Physicians and American Society of Clinical Oncology (publication pending) has led to wider acceptance and development of best practice for the needs of SGM patients. Increased education in health science graduate programs and continued medical education as well as JCAHO standards on SGM cultural competency have moved forward the health and well-being of SGMs since the publication of the 2011 Institute of Medicine report. The American Medical Association has recently announced a new set of policies to better serve transgender patients. The American Nursing Association developed Diversity Awareness in Professional Nursing, which has many resources to support nursing practice for SGMs.

Despite the gains in access to health insurance for SGM individuals and greater protection for visitation rights of SGM patients and their families of choice, there remains uncertainty about future progress and governmental support for improving the health care of SGMs. This makes collaboration with SGM communities even more crucial in developing best practice guidelines as we learn more through inclusive HPC

- Center of Excellence for Transgender Health—<http://transhealth.ucsf.edu/>
- Hospice Foundation of America LGBT Resources—<https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/How-to-Choose/LGBT-Resources>
- Lambda Legal Tools for Life and Financial Planning—<http://www.lambdalegal.org/publications/take-the-power>
- LGBT Best and Promising Practices for Cancer Care for LGBT Patients and Families Throughout the Cancer Continuum—<http://www.lgbthealthlink.org/Cancer-Best-Practices>
- LGBT Hospice and Palliative Care Network—<https://lgbthpm.org/resources/>
- National Resources Center on LGBT Aging—<http://LGBTagingcenter.org/resources>
- Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders—<http://sageusa.care/>

Fig. 1. Resources to improve the quality of hospice and palliative care for sexual and gender minority patients and families. LGBT = lesbian, gay, bisexual, and transgender.

Table 2
Future Directions

- Collaboration with key stakeholders (federal/state government, community groups and large nonprofits, health care providers, patient advocacy groups) to generate professional standards
- Accessible standardized resources that are integrated within health care systems
- Research that is inclusive of SOGI measures
- Increased research funding to support SOGI research in HPC
- Supportive environments encouraging disclosure in general and in HPC settings
- Inclusion of families of choice
- Zero tolerance for discrimination in light of rollbacks expected/professional standards
- Continued competency training in LGBT care for all staff
- Ensured compliance with changing legal landscapes

SOGI = sexual orientation and gender identity; HPC = hospice and palliative care; LGBT = lesbian, gay, bisexual, and transgender.

research. Table 2 summarizes future directions in research, policy, education, and patient care that are needed to provide equitable care for SGMs in HPC settings. Figure 1 presents resources to improve the quality of HPC for SGM patients and their families.

Conclusions

SGMs comprise a diverse group of individuals and communities that historically have remained largely invisible. This invisibility has hurt the health and well-being of SGM patients and families and led to significant health care disparities even in HPC settings.^{29,47–49} Patient-centered care that focuses on patients' dignity and self-determination is at the core of HPC medicine. This can only happen if HPC providers make it safe for SGM patients to disclose their status and introduce their spouses, significant others, and families of choice, and if we are equipped to address the unique barriers and issues that may arise. The consistent barriers to high-quality care have been well described in prior research. Implementing the recommended guidelines and practices will significantly reduce the health care disparities experienced by SGMs in HPC settings.

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References

1. Griggs J, Maingi S, Blinder V, et al. American Society of Clinical Oncology position statement: strategies for reducing cancer health disparities among sexual and gender minority populations. *J Clin Oncol* 2017;35:2203–2208.
2. Daniel H, Butkus R. Lesbian, gay, bisexual, and transgender health disparities: executive summary of a policy position paper from the American College of Physicians. *Ann Intern Med* 2015;163:135–137.

3. Burkhalter J, Margolies L, Sigurdsson HO, et al. The national LGBT cancer action plan: a white paper of the 2014 national summit on cancer in LGBT communities. *LGBT Health* 2016;3:19–31.
4. Lambda Legal. When health care isn't caring: lambda legal's survey of discrimination against LGBT people and people with HIV. New York: Lambda Legal, 2010. Available from www.lambdalegal.org/health-care-report. Accessed March 15, 2017.
5. Institute of Medicine. The health of lesbian, gay, bisexual, and transgender people building a foundation for better understanding. Washington, DC: National Academy of Science, 2011.
6. Lick D, Durso LE, Johnson KL. Minority stress and physical health among sexual minorities. *Perspect Psychol Sci* 2013;8:521–548.
7. Anderson JS, Vajdic C, Grulich AE. Is screening for anal cancer warranted in homosexual men? *Sex Health* 2004;1:137–140.
8. Dibble SL, Roberts SA, Nussey B. Comparing breast cancer risk between lesbians and their heterosexual sisters. *Womens Health Issues* 2004;14:60–68.
9. Centers for Disease Control and Prevention 2013. HIV among gay, bisexual and other men who have sex with men. Atlanta, GA.
10. Acquaviva K. LGBTQ-Inclusive hospice and palliative care: a practical guide to transforming professional practice. New York, NY: Harrington Park Press, 2017.
11. Patterson JG, Jobson JM, Bowen DJ. Measuring sexual and gender minority populations in health surveillance. *LGBT Health* 2017;4:82–105.
12. Cahill SR, Makadon HJ. If they don't count us, we don't count: trump administration rolls back sexual orientation and gender identity data collection. *LGBT Health* 2017;4:171–173.
13. Bjarnadottir RI, Bockting W, Dowding DW. Patient perspectives on answering questions about sexual orientation and gender identity: an integrative review. *J Clin Nurs* 2017;26:1814–1833.
14. Stein GL, Beckerman NL, Shearman PA. Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. *J Gerontol Soc Work* 2010;53:421–435.
15. Price E. Coming out to care: gay and lesbian carers experience of dementia services. *Health Soc Care Community* 2010;2:160–168.
16. Katz M. Gay and lesbian patients with cancer. *Oncol Nurs Forum* 2009;36:203–207.
17. Bristowe K, Hodson M, Wee B, et al. Recommendations to reduce inequalities for LGBT People facing advanced illness: ACCESSCare national qualitative interview Study. *Palliat Med* 2018;32:23–35.
18. Matthews AK. Lesbians and cancer support: clinical issues for cancer patients. *Health Care Women Int* 1998;19:193–203.
19. Matthews AK, Peterman AH, Delaney P, Menard L, Brandenburg D. A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer. *Oncol Nurs Forum* 2002;29:1455–1462.
20. Fobair P, O'Hanlon K, Koopman C, et al. Comparison of lesbian and heterosexual women's response to newly diagnosed breast cancer. *Psychooncology* 2001;10:40–51.

21. Hash KM, Netting FE. Long-term planning and decision making among middle and older gay men and lesbians. *J Soc Work End Life Palliat Care* 2007;3:59–77.
22. Johnson MJ, Jackson NC, Arnette JK, Koffman SD. Gay and lesbian perception of discrimination in retirement facilities. *J Homosex* 2005;49:83–102.
23. Movement advancement project and services and advocacy for gay, lesbian, bisexual and transgender elders 2010. Improving the lives of LGBT older adults. Available from http://www.sageusa.org/uploads/AdvancingEqualityforLGBT_Elders. Accessed November 25, 2017.
24. Biller R, Rice S. Experiencing multiple losses of persons with AIDS: grief and bereavement issues. *Health Soc Work* 1990;15:283–290.
25. Goodkin K, Blaney NT, Feaster DJ, Baldcwicz T. A randomized controlled clinical trial of a bereavement support group intervention in Human Immunodeficiency Virus Type-1-seropositive and –seronegative homosexual men. *Arch Gen Psychiatry* 1999;5:52–59.
26. Varner A. Spirituality and religion among lesbian women diagnosed with cancer. A qualitative study. *J Psychosoc Oncol* 2004;22:75–89.
27. Cartwright C, Hughes M, Lienert T. End-of-life care for gay, lesbian, bisexual and transgender people. *Cult Health Sex* 2012;14:537–548.
28. Harding R, Epiphanou E, Chidgey-Clark J. Needs, experiences, and preferences of sexual minorities for end-of-life care: a systematic review. *J Palliat Med* 2012;15: 602–611.
29. Curie M. Hiding who I am: the reality of end of life care for LGBT people, 2016. Available from <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf>. Accessed April 1, 2017.
30. Witten T. End of life, chronic illness and trans-identities. *J Soc Work End Life Palliat Care* 2014;10:34–58.
31. National Council for Palliative Care and Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organizations: Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life. London: National Council for Palliative Care, 2011.
32. Stinchcombe A, Smallbone J, Wilson K, et al. Healthcare and end-of-life needs of lesbian, gay, bisexual, and transgender (LGBT) older adults: a scoping review. *Geriatrics* 2017;2:13.
33. Rawlings D. End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals. *Int J Palliat Nurs* 2012;18:29–34.
34. Lawton A, White J, Fromme EK. End-of-life and advance care planning considerations for lesbian gay, bisexual and transgender patients #275. *J Palliat Med* 2014;17:106–108.
35. Eliason MJ, Streed C, Henne M. Coping with stress as an LGBTQ+ health care professional. *J Homosex* 2017;1–18, <https://doi.org/10.1080/00918369.2017.1328224>. [Epub ahead of print].
36. O'Mahony S, Maingi S, Scott B. Report of a survey of palliative medicine clinicians' experience of workplace discrimination related to sexual orientation and gender identity, professional development needs and priorities for improved palliative care for sexual minority patients and their families. Poster Presentation at Gay and Lesbian Medical Association Annual Conference, Portland, Oregon, 2015.
37. Buchting FO, Margolies L, Bare MG, et al. LGBT best and promising practices throughout the cancer continuum. Fort Lauderdale, Florida: LGBT Health Link, 2015. Available from <https://www.lgbthealthlink.org/Assets/U/Documents/Cancer-Best-Practices/cbpp-april2016.pdf>. Accessed March 1, 2017.
38. Makadon H. Improving healthcare for the lesbian and gay communities. *N Engl J Med* 2006;354:895–897.
39. Tesar CM, Rovi SL. Survey of curriculum on homosexuality/bisexuality in departments of family medicine. *Fam Med* 1998;30:283–287.
40. American Geriatrics Society Ethics Committee. American Geriatrics Society care of lesbian, gay, bisexual and transgender older adults position statements: American Geriatrics Society Ethics Committee. *J Am Geriatr Soc* 2015;63: 423–426.
41. Maingi S, O' Mahony S, Bare M, et al. National guidelines for the best practices in palliative and end-of-life care for lesbian, gay, bisexual, and transgender cancer patients and their families. *J Clin Oncol (Meeting Abstracts)* 2015; 33:126.
42. Green LW, Ottoson JM, Garcia C, Hiatt RA. Diffusion theory and knowledge dissemination, utilization, and integration in public health. *Annu Rev Public Health* 2009;30: 151–174.
43. Dobbins M, Robeson P, Ciliska D, et al. A description of a knowledge broker role implemented as part of a randomized controlled trial evaluating three knowledge translation strategies. *Implement Sci* 2009;4:23.
44. Leviton LC, Gutman MA. Overview and rationale for the systematic screening and assessment method. *New Dir Eval* 2010;125:7–31.
45. The World Professional Association for Transgender Health. Standards of care for the health of transsexual, transgender, and gender nonconforming people. 7th Version, 2011. Available from <http://www.wpath.org>. Accessed March 23, 2017.
46. The gay and transgender pay gap, 2012. Available from www.americanprogress.org/issues/lgbt/news/2012/2014. Accessed July 4, 2017.
47. Boehmer U, Case P. Physicians don't ask, sometimes patients tell: disclosure of sexual orientation among women with breast carcinoma. *Cancer* 2004;101:1882–1889.
48. Available from <http://gensilent.com/>. Accessed December 15, 2017.
49. Smolinski KM, Colon Y. Silent voices and invisible walls: exploring end of life care with lesbians and gay men. *J Psychosoc Oncol* 2006;24:51–64.