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Palliative care needs, concerns, and affirmative strategies for the LGBTQ population

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***Abstract*:** The Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning population, also known as sexual and gender minorities, are an incredibly marginalized and vulnerable population that have been disproportionately affected by the provision, delivery, and optimal access to high-quality medical care including palliative, hospice, and end-of-life care. The long-standing and unique experiences shaped by positive and negative historical events have led to a better understanding of significant barriers and gaps in equitable healthcare for this population. The intersection of both internal and external stressors as well as minority identities in the context of discriminatory political and societal infrastructures have resulted in variable health outcomes that continues to be plagued by economic barriers, oppressive legislative policies, and undesirable societal practices. It could not be more urgent and timely to call upon the government and healthcare systems at large to execute reforms in policies and regulations, engage in cultural competency training, and promote cultural shifts in beliefs, attitudes, and practices that will ultimately recognize, prioritize, and address the needs of this population. After all, health care access is a universal right regardless of personal, social, political, and economic determinants of comprehensive medical care.

Keywords: advance directives, bisexual, gay, health disparities, lesbian, LGBTQ, life-limiting illness, palliative care, queer, questioning, sexual and gender minorities, transgender

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Introduction

According to the 2017 Gallup Poll conducted by the Williams Institute, sexual and gender minorities (SGMs) account for 4.5% of the 325.1 million Americans. About a third of the SGMs identified as Latino or Black while adults older than 50 years and above comprised about a quarter.[1] It is expected that the older Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning (LGBTQ) adult population will continue to rise over the next 10 years.[2]

Given the significant proportion of LGBTQ adults, there are still ongoing gaps to support public health research and advocacy to address their core needs and concerns.[3] In 2011, the Institute of Medicine identified that there are significant healthcare disparities affecting the LGBTQ population and that there are opportunities to advance research in this area.[4] There is underreporting of pertinent and inclusive demographic data (e.g. sexual orientation and gender identity) toward the LGBTQ population. This gap further heightens the risk for more invisibility of this marginalized population even in basic aspects of daily life including healthcare. There are currently insufficient data on the gender non-binary (GNB) or gender non-conforming (GNC) subgroup. Other *minority within minority groups* include the older adults and those living with HIV/AIDS who are also disproportionately impacted by healthcare resources.[5] There is a continuing need to provide high-quality and comprehensive medical care including palliative, hospice, and end-of-life (EOL) care. Under President Biden's administration in the United States, there is renewed hope to address the healthcare needs of the LGBTQ population by enhancing non-discriminatory policies and investing in more research and resources to address the unique needs and priorities of this population. This review article aims to provide a conceptual framework in understanding the palliative care needs of the LGBTQ population and how the unique identities and stressors could impact its provision and delivery. This article also provides recommendations on affirmative and inclusive strategies to care for them in a holistic and compassionate way.

Understanding the LGBTQ population: review of essential concepts impacting overall health including palliative, hospice, and EOL care

LGBTQ people have experienced multiple societal barriers to living life fully and safely as well as aging gracefully. An initial step for any healthcare provider is to understand the unique and long-standing historical events and milestones (Table 1) that this population has experienced over their lifetime including trauma, widespread oppression, prejudice, victimization, and abuse.[5,6] A 2019 United States poll showed that the LGBTQ population have been subjected to intolerance and ostracization by society at large and therefore has faced heightened discrimination including vicious hate crimes.[7] There are multiple internal and external stressors that contribute to the marginalized identities of this population. Table 1 shows an abridged version of significant milestones that the LGBTQ population born in the United States before 1950 has gone throughout their lifetime. These events have shaped how they might perceive access to various aspects of healthcare. Furthermore, these historical points may serve as triggers for physical and psychological trauma thereby delaying or avoiding medical care and not disclosing sexual orientation and gender identity (SOGI) status to healthcare providers.

Historical timeline for the LGBTQ population in the United States

The following general concepts aim to allow medical providers to have a lens of understanding, sensitivity, and empathy while caring for their LGBTQ patients:

1. *Intersectionality*. This refers to the confluence of numerous external and internal factors that shape the experience and identities of the LGBTQ adult. These factors may have equal or variable degree of influence that subjects them to prejudice and discrimination.[9] Intersectionality provides a structural framework to understand how these factors are interrelated and oftentimes interdependent. There are polarizing systems of privilege and oppression at both the general and microscopic levels.[10] For example, an older adult transgender and bisexual woman of color with metastatic cancer to the bone requiring a cane to ambulate maybe discriminated against due to her disability, older age, bisexual orientation, Black race, and gender among others (see Figure 1).
2. *Minority Stress Model*. Initially conceptualized by Ilan Meyer, this refers to the excess stress to which individuals from stigmatized social categories are exposed as a result of their social and minority position.[11] Moreover, Meyer conceptualized these stressors as unique and described them in three categories: (1) *additive* to general stressors that are experienced by all people and therefore require adaptations above and beyond those required of the non-stigmatized; (2) *chronic* in that they are related to relatively stable social structures such as laws and social policies; and (3) *socially based* in that they stem from social and structural forces rather than individual events or conditions.[11] A concrete illustration is an American LGTBQ older adult with advanced heart disease who was born in the 1950s and whose life course was influenced by both positive and negative effects of the Stone Wall riots and the Harvey Milk assassination. Over time, the Supreme Court Ruling on same-sex marriage in 2015 would have also impacted this individual and the significant other who would have waited for decades to be recognized at a federal level. The various stressors faced by this individual would have resulted in significant physical and mental health outcomes.
3. *Lived experiences*. There are two operational theories that can complement the understanding of the minority stress model. Aldwin and Gilmer described two theories namely the *Life Course Theory* and *Goal-Oriented Theory*.[12] While the former posits that transitional points are impacted by society, history, and gender roles, the latter

Table 1. Historical timetable of important milestones in American LGBTQ history.[8]

Date	Milestone
1950	• US Senate issued: 'Employment of homosexuals and other sex perverts in government' • First gay organization, Mattachine Society, established in California
1952	• American Psychiatric Association (APA) listed homosexuality as a sociopathic personality disturbance • Christine Jorgensen became the first visible American transgender woman who underwent sex reassignment surgery
1953	US President Eisenhower banned homosexuals from working for the federal government
1956	• Psychologist Evelyn Hooker concluded that heterosexual and homosexual persons did not differ significantly in adjustment • James Baldwin published first novel on bisexuality
1966	Compton Cafeteria riot broke out in San Francisco when transgender women were denied service and arrested for wearing feminine clothing
1967	Look Magazine article released: 'The Sad Life of the Homosexual'
1969	Stone Wall Riots: birth of the modern gay rights movement
1970	First Gay Liberation March held in New York City
1973	APA voted to remove homosexuality as a psychiatric disorder
1977	Harvey Milk was elected as the first openly gay public official to the San Francisco Board of Supervisors
1979	National march in Washington for lesbians and gays
1982	Nearly 800 people were infected with Gay-Related Immunodeficiency Disorder later known as HIV-AIDS
1986	US Supreme Court upheld the rights of states to criminalize between consenting same sex adults
1987	National AIDS advocacy group, ACT-UP was founded
1993	Military issued 'Don't Ask, Don't Tell' policy
1996	President Clinton signed 'Defense of Marriage Act' defining marriage between a man and a woman
1997	Ellen Degeneres came out publicly on national TV as the first gay/lesbian lead character in a popular show
1998	Matthew Shepard was brutally murdered in Wyoming USA
2003	US Supreme court ruled that sodomy laws are unconstitutional
2004	Massachusetts was the first US state to legalize gay marriage
2006	Attorney Kim Coco Iwamoto became the first transgender woman to be elected at a state level office in Hawaii USA
2011	US President Obama administration ended Don't Ask Don't Tell in the military
2013	US Supreme Court struck down 'Defense of Marriage Act'
2015	• US Supreme Court legalized same sex marriage • Cincinnati Ohio banned conversion therapy for LGBTQ youth
2016	US President Obama designated the new Stone Wall as a national monument
2017	Trump administration rolled back SOGI information on national surveys and demographic questionnaires
2020	US Supreme Court voted against discrimination by employers on the basis of sexual orientation or gender identity
2021	The US Equality Act passed in Congress

Source: Obtained with permission, Greg Hinrichsen PsyD. (https://www.glsen.org/sites/default/files/LGBTQ-History-Timeline-References.pdf).

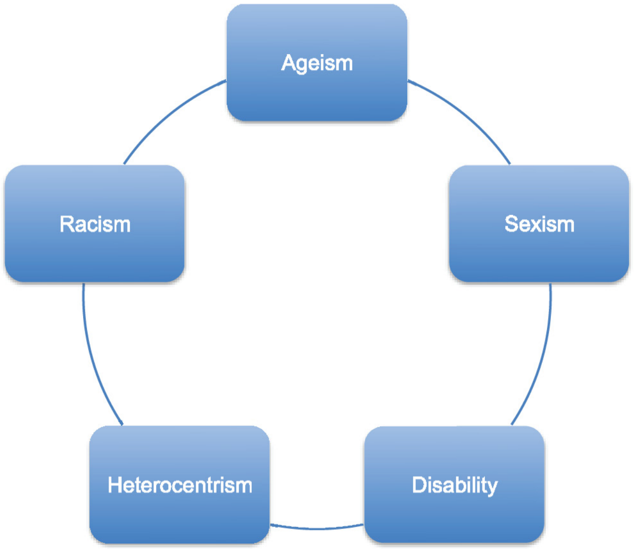

Figure 1. The intersectionality framework (created by Noelle Marie Javier MD).

presupposes that as adults evolve over time, their experiences are shaped by challenges and triumphs as they strive to pursue life's goals while striving to develop their core sense of being.[12] A study by Witten[13] showed an association between discrimination and sociocultural factors that affect the life trajectory of an LGBTQ adult. For example, an LGBTQ adult who grew up at a time when homosexuality was considered a mental health disorder and traumatized by conversion and other therapies will have a different life journey compared to another LGBTQ adult living in the current century with the depathologization of homosexuality and the existence of more progressive and non-discriminatory laws around healthcare, employment, education, and public accommodations among others. The lived experiences of these two adults are invariably shaped by the historical, social, and political context they both grew up in and may lead to significant impact on their overall health outcomes as the convergence of multiple minority stressors become apparent in day-to-day living.

4. *Stigma toward SGMs*. A concept best described by sociologist Erving Goffman as 'undesired differentness' within a specific social interaction or across many social interactions.[14] Moreover, the characterization of the state of differentness may be based on abominations of the body, blemishes of individual character, and tribal membership. This can take many forms ranging from structural to personal or individual. Herek further distinguishes stigma based on sexual orientation (sexual stigma) and gender identity (gender minority stigma). Structural gender minority stigma leads to the invisibility of this vulnerable population and furthermore oppressed when visibly represented as problematic, abnormal, inferior, and unnatural beings. Stigma can take many forms such as enacted (e.g. outright abuse) versus perceived (e.g. living in stealth/closeted for fear of explicit discrimination) versus internalized (e.g. self-loathing or punishment for being LGBTQ). These can then result in deleterious health effects that are additive to general health risks of the LGBTQ population.[15] The Minority Stress Model provides a great example on the overlapping and intersectional effects of multiple stigmas that the LGBTQ population face. For example, a transgender man of color experiences personal, interpersonal, and structural stigmas by virtue of being transgender. He could experience internalized transphobia, be isolated from his nuclear family, and discriminated against at work or in public accommodations for living authentically. The accretion of all of these stigmas could lead to undesirable physical and mental health outcomes such as cardiovascular disease and suicide, respectively.
5. *Resilience and robustness*. The LGBTQ population has developed affirmative health-promotion strategies such as resilience and robustness in spite of multiple stressors and stigmas. *Resilience* is defined as the person's ability to mitigate the adverse impact of stress while successfully thriving in society.[16] The three factors for resilience development are supportive environments, protective interpersonal relationships, and intrapersonal characteristics.[17,18] Coping is distinctive from resilience in that this refers to the effort an individual puts into adapting or responding to stress.[19] Resilience has also been defined by Singh and McKleroy[20] as a set of learned behaviors and interpersonal relationships that precedes one's ability to cope with adversity. While resilience may be described as essentially stress-buffering,[19–22] *Robustness* pertains to the individual or system's ability to resist disruption from external stressors.[23] Examples of adaptive resources that lead to resilience

and robustness include spirituality, community supports, activism, and societal infrastructures that allow the individual to feel supported.[23] These were especially evident in the Trans MetLife Survey highlighting that older transgender adults tapped into internal and external resources for resilience and robustness allowing for successful aging to some degree.[23] Meyer has observed that gay men of color do not necessarily have a higher risk for mental health issues in part because of resilience resources stemming from strong intrapersonal coping skills (e.g. religiosity and faith) and community connections and supports (e.g. religious congregations).[24]

Overview of healthcare barriers, inequities, and disparities

Physical health disparities

The impact of the oppressive and stigmatizing historical points experienced by the LGBTQ population has resulted in challenging and oftentimes undesirable relationships with their healthcare providers. Although SOGI data collection may potentially induce fear among LGBTQ people for possible discrimination in healthcare settings, there are data to support that its collection allows for visibility resulting in a nuanced and customizable approach in addressing the unique healthcare needs of this population.[25] One large study showed that about half of SGM patients and more than two thirds of patients with transgender experience have received disproportionate medical care in various clinical settings.[26] Another study of over 200,000 healthcare providers showed a heteronormative preference in taking care of LGBTQ patients.[27] Discrimination in healthcare is even more overt among transgender and gender nonconforming (TGNC) individuals as evidenced by a 2015 survey of transgender participants in the United States.[28] It was also reported that these respondents had to educate medical providers about transgender health. Clinical providers were observed to have used abusive language in about 5% of them. The intersectionality of multiple minority identities leads to significant minority stress that have led to limited medical care access and negative outcomes for these individuals.[29–31] For example, SGM people of color may experience mental health distress resulting from multiple stigmas and prejudices related to their race, sexual orientation, and gender identity.[32,33] This could lead to direct and indirect effects of mental health such as depression, anxiety, insomnia, and alcohol drinking toward known physical conditions like cardiovascular disease and liver dysfunction.[34] In addition, LGBTQ people and especially the older LGBTQ adults often live with limited means that further impact access to the provision of good healthcare resources such as medical insurance, food access, transportation, and safe housing.[35,36] There is also a higher proportion of disability compared to their heterosexual counterparts as evidenced by SGM women having a higher likelihood of experiencing physical disability.[37] Moreover, bisexual and lesbian older women are more likely to engage in high-risk health behaviors (e.g. smoking and alcohol drinking).[38] Furthermore, bisexual women have invariably poorer health indicators than lesbian women.[39] In general, LGBTQ women are at high risk for coronary artery disease (CAD), obesity, gynecologic and breast neoplasms in contrast to straight women.[39] SGM men have a higher proportion of having cardiovascular disease, hypertension, diabetes, psychological distress, and physical disability.[37–39] Bisexual older men and transgender older adults reported poorer overall physical health compared to gay older men and cisgender older adults, respectively. Moreover, older bisexual and gay men engage in cigarette smoking, alcohol drinking, and risky sexual behaviors.[38,39] Among transgender individuals, Kenagy's study found that transgender women have a higher incidence of mental health issues, immunodeficiency disorders, and different types of abuse.[40]

Inasmuch as the physical health disparities are significant to point out, it is equally important to identify protective factors that allow this population to thrive amid their illnesses. A 2020 study showed that SGMs have a higher prevalence of engaging in low leisure-time physical activity compared with their heterosexual cohorts. Exercise not only improves the general sense of well-being but also provides benefits in regulating blood pressure, reducing undesirable body fat, improving insulin action, and mitigating further functional disability.[41,42] Studies have also pointed that a good support network could facilitate an active engagement in health-promoting lifestyle such as diet and exercise.[43] Among older LGBTQ adults, health-promoting behaviors such as substance non-use, physical activity, leisure activity, and participation in religious and spiritual activities have been observed.[44]

Palliative care implications on physical health outcomes in serious illness

A key step in providing holistic palliative care is collecting SOGI information. Not only will this create a therapeutic and trusting relationship but will also provide a deeper understanding of the LGBTQ patient's intersectional identities, multiple minority stressors, and lived experiences including stigma and resiliency.[45] SOGI collection through routine intake forms on paper or via the electronic medical record is essential in creating systemic change toward LGBTQ-inclusive healthcare.[46] In addition, it is recommended that palliative care providers invite and allow SOGI disclosure in a safe and comfortable space. Utilizing respectful and sensitive ways to elicit SOGI information allows for an organic conversation and relationship to evolve. These actions result in greater comfort level, higher overall healthcare satisfaction rates, improved patient-caregiver-provider alignment, better sense of well-being, and enhanced quality of care for the LGBTQ patients and their caregivers.[47] Furthermore, this will allow for a tailored approach in considering their unique experiences. Obtaining SOGI information opens up a gateway to recognize the patient's values, healthcare needs, existential/spiritual issues, and priorities in healthcare. Intrinsic to empathic communication and relationship building is the thoughtful inclusion of informal caregivers and families of choice. Comprehensive palliative care support could then be expanded to include implementation of resources needed for documentation, legal provisions in advance care planning (ACP), and navigating challenges in various medical settings.[48] After obtaining SOGI, the next step involves understanding the lived experiences of the LGBTQ patients through their experiences of multiple external and internal stressors, implicit and explicit bias, oppressive and discriminatory encounters, and destructive healthcare systems. A core aspect in history taking is to explore the supportive networks and resources from both individual and community levels. It is reported that SGM men of color have greater resiliency compared with their White cohorts.[19] Hence, looking into both stressors and positive factors that allow LGTBQ people to thrive and survive could play an impact on the care plan and future physical health outcomes. A customized palliative care plan can be created to focus on (1) physical, psychological, and spiritual symptom management; (2) early utilization of other members of the palliative care team such as social workers and chaplains; (3) timely referral to hospice services; and (4) ACP to include funeral planning and disposition of remains. The physical examination component of a palliative care encounter starts with showing respect by obtaining permission to proceed with the examination and allowing the patients to take the lead based on comfort level. For instance, for TGNC individuals, the identification and labeling of body parts may be extremely sensitive and fraught with dread and anxiety, as this action could be deemed invasive and inappropriate. It is essential to openly discuss the purpose of doing the examination. Allowing patients to teach providers about naming anatomic parts and the significance of respectful touch will foster trust and build rapport.

For LGBTQ patients who are now facing serious illness, significant blame and shame could serve as triggers for not accessing timely medical care. Formulating a comprehensive care plan for addressing symptom distress and quality of life issues for LGBTQ patients with serious illness also requires a timely approach to ACP. Stein and Bonuck's 2001 study identified that in a sample of 575 lesbian and gay respondents, about 90% of them had high levels of knowledge on the use of living wills and 72% of them understood the necessity for health care proxy (HCP) designation. However, only 38% completed a living will and 42% of them appointed a HCP.[49] ACP refers to the dynamic process of verbal and legal expression and documentation of an individual's preferences for care should the individual become incapacitated when faced with serious illness. Specific examples of ACP include living will, HCP, or combination of both. The FIVE Wishes document formalizes the care preferences according to a patient's goals and values and reflected as five wishes for medical care. This is a valid document that can cross state lines and provide guidance to healthcare providers.[50] On the contrary, the medical orders for life-sustaining treatment (MOLST), also known as provider order for life-sustaining treatment in other states (POLST), is a similar yet unique portable document that takes into account the patient's wishes and preferences for care in very specific medical situations.[51,52] MOLST AND POLST forms are very targeted on interventions including antimicrobial therapy use, transfusions of blood products, artificial nutrition/hydration, and code or resuscitation status. The state-specific HCP form or durable power of attorney (POA) for health is the designated spokesperson and decision maker for an incapacitated patient. The person(s) chosen could be family members, relatives, and friends. In 2012, Cartwright cited specific challenges to successful documentation of care preferences. These included inadequate knowledge on EOL legal rights, lack or prioritization, proper timing of conversations, and heteronormative assumptions made by medical providers.[53] Hughes and Cartwright[54] found that TGNC patients avoided EOL care decision making. Having an understanding of overall goals of care in the setting of big picture planning will allow for appropriate utilization and delivery of palliative and hospice care services that may be provided in a variety of settings such as home, inpatient, outpatient, and long-term care facilities depending on other variables.

Mental health disparities

LGBTQ people also suffer from unwanted and distressing mental health outcomes that have been associated with chronic traumatic discriminatory practices toward them.[6] Same-sex attraction was once described as 'paraphilia' or 'sexual orientation disturbance' in the psychiatric literature.[55] Consequentially, aggressive psychiatric interventions such as conversion and shock therapies to 'correct or cure their mental disorders'[56,57] have resulted in negative and traumatic experiences for this population. In the past, *DSM* referred to Transgender Identity as a 'Gender Identity Disorder' until it was renamed Gender Dysphoria 8 years ago.[58] This term describes the persistent emotional discomfort and stress that occurs among individuals whose anatomy does not match their gender identity. Although the current terminology maybe less stigmatizing, its purpose as a pathologic classification allows for transgender persons seeking medical care to access insurance coverage and reimbursement for transition-related medical and surgical therapies.

There is some evidence that links genetic vulnerability or susceptibility to these experiences. Overt acts of abuse lead to depression, anxiety, suicide, and other mental health issues.[59] Bisexual patients showed worse psychological outcomes compared with gay men and women. Gay and bisexual men were observed to have greater risk for depression, suicidal ideation, and alcohol abuse compared to lesbian and bisexual women.[59] Furthermore, Wight's study confirmed more depression for gay men who have experienced internalized gay ageism.[60] For the transgender population, they have a great degree of poor psychological outcomes compared to cisgender patients.[39] In fact, Fredriksen-Goldsen found that transgender patients reported to have more depression than the rest of the SGM cohorts.[39] A 2013 study specifically looking at suicidal ideation showed that about a third of SGM participants thought about committing suicide.[39] It is important to note that the occurrence of suicide attempts was more apparent in SGM respondents younger than 60 years old.[2,59] A large study of transgender respondents showed that 41% of respondents reported suicide attempts over their lifetime that were associated with external stressors such as unemployment, physical harassment, poverty, and physical and sexual assault.[61] This was affirmed 4 years later by the 2015 US Transgender Survey.[28] Moreover, there are two other major health problems linked to psychological distress including substance use disorder (SUD) and high-risk sexual behavior that are commonly influenced by numerous factors such as mood disorder, abuse, and discrimination, among others.[62] Despite the statistics shown, there is a higher likelihood for LGBTQ persons seeking professional help compared to non-LGBT group.[63,64]

Palliative care implications on mental health outcomes. It is undeniable that the implications on mental health are quite jarring given the data that exist in the literature. That said, there are a number of positive coping and resilient mechanisms that palliative care clinicians should be knowledgeable about. Examples include community support networks, spiritual affiliations, and resiliency.[65] Monin and colleagues[66] concluded that older SGM veterans are at greater risk for social isolation though more resilient overall compared with the younger cohort. The interprofessional members of the palliative and hospice care teams such as social workers, chaplains, and bereavement counselors are well positioned to offer tremendous support by identifying supportive resources that will allow a multidimensional approach to medical care. Timely referrals to psychologists, psychiatrists, and other mental health experts can assist the LGBTQ population with serious illness by recommending counseling, psychotherapies, and pharmacotherapy when necessary. Early referrals to support groups can be offered as well. Mobilizing statewide mental health organization referrals may also allow for additional structured community supports to patients and their caregivers. In a 2020 study by

Stein and colleagues,[67] among 865 hospice and palliative care providers and clinicians, 53.6% of them thought that LGB patients were more likely than non-LGB patients to experience discrimination at their institution while 15% of them observed that the spouse/partner of LGBT patients had their treatment decisions disregarded or minimized or overtly disrespected. It is also important to address grief and bereavement including disenfranchised grief for patients and families experiencing serious illness. Concrete interventions include timely referral to bereavement counselors, support groups, mental health counselors, and chaplaincy among others.

Regulatory and policy challenges and limitations

The evolving trajectory of governmental regulations on expanding protective policies for this population has been rooted in years of restrictive laws and practices that have resulted in further marginalization of this population. As the country progressed however, we have seen significant strides in the creation and implementation of regulations, policies, and practices that reflect more inclusivity and acceptance. A specific example is the 2014 California *Assembly Bill 496* that required clinical providers to receive cultural competency training on SOGI information.[53] This orchestrated a call to address gaps in the medical providers' training in LGBTQ medicine as well as the provision of relevant resources.[68,69] Despite these changes, there is an ongoing fight for civil rights and equity especially seen in the current pandemic of COVID-19 and the aftermath of the George Floyd tragedy. With the previous Trump presidency, there have been numerous attempts to amend state and federal legislative policies against the protection of LGBTQ individuals by invoking religious rights and beliefs to justify the refusal and abandonment of health and psychosocial services.[70,71] This included sweeping revisions and further restrictions on health care access such as medical insurance and other service benefits.[71] In addition, the Trump administration had argued before the Supreme Court that gender-based protections under Title VII of the Civil Rights Act of 1964 do not apply to claims of discrimination based on sexual orientation or gender identity.[67] Moreover, there is also the application of the *conscience rule* which serves as an inflammatory practice that allows healthcare professionals receiving federal support to decline medical care that goes against their moral or spiritual beliefs.[67] Finally, there is a roll-back on data collection of SOGI information in national surveys and government programs that will impact their visibility as essential members of this country.[70,71] With US president Biden, there is renewed hope that more inclusive and affirmative healthcare policies for the LGBTQ population will be reinstated. A couple of major landmarks are the 2020 US Supreme Court ruling that employers cannot discriminate employees based on their SOGI. In April 2021, the Equality Act has been passed in the House of Congress. If passed by the US Senate, this will provide federal protections for the LGBTQ population in various aspects of life such as housing, education, employment, public accommodations, and healthcare among others.[71–73]

Palliative care implications on the regulatory and policy barriers. Healthcare organizations that offer hospice and palliative care services could ensure inclusivity and equity by upholding nondiscrimination and zero-tolerance to prejudicial policies within their respective systems. There should be a safety net for all staff, patients, and their families/caregivers to report evidence of discriminatory and hostile practices without fear of retaliation and punishment. There should also be systems of accountability within the organizations that will include additional measures of remediation and further training and education.[47] It is vital to implement visible indicators of inclusion such as rainbow flags and system policies online and on-site within care settings to reassure the LGBTQ patients that they are in a safe environment. Ongoing staff training is necessary to affirm commitment to high-quality care. It is also worthwhile for these organizations to build a community outreach and partnership so that appropriate services and resources could be offered in a meaningful and effective manner. Beyond the institutional settings, leaders of palliative care organizations such as the American Academy of Hospice and Palliative Medicine and the Center to Advance Palliative Care should continue to engage in efforts to advocate and lobby for major changes to the provision of equitable healthcare at the state and federal levels.

Economic factors

A major contributor to the existing healthcare inequities involves economic factors such as the presence or absence of financial resources. The geriatric LGBTQ adults face economic hardships more than their younger counterparts.[61] About 30% of them live at or below the economic threshold.[65] Older transgender adults are even more disproportionately affected by financial constraints.[38] Hence, access to appropriate medical and surgical treatments remain challenging for this population. In one study, significant differences were noted in the diverse subgroups of SGM older adults.[74,75] The expansion of the Affordable Care Act allowed for non-discriminatory health care by: (1) providing protection on medical insurance plans, (2) expanding Medicaid programs to all persons at or below 133% of the federal poverty level, and (3) providing financial subsidies to help those making between 100% and 400% of the federal poverty level purchase insurance on the federal and state market place exchanges.[76]

Palliative care implications on economic barriers. A major step in providing inclusive and affirmative palliative care is to reassure LGBTQ patients that they will receive high-quality care without regard to their financial status and insurance coverage. The palliative care social workers have a vital role in exploring the financial situation of patients and their families/caregivers especially when this affects the provision and extension of healthcare services as well as transitions in care settings along the continuum of care. Healthcare organizations at large have unique positions to expand coverage of hospice and palliative care services regardless of financial capabilities and insurance coverage.[77,78] Often times these organizations accommodate indigent and undocumented patients through charity care services that would eliminate interruption in palliative care services. With federal protections looming in the horizon, there is hope that all affirmative medical and surgical therapies for LGBTQ patients will eventually have medical insurance coverage.

Affirmative, inclusive, compassionate, and interprofessional approach to high-quality palliative care

The provision and delivery of affirmative, inclusive, compassionate, and interprofessional high-quality palliative care builds on the construct of *cultural humility* which posits that openness, self-awareness, egoless, and supportive interactions marked by self-reflection and self-critique by the clinical providers is a fundamental responsibility for care toward SGM patients.[79] By incorporating the salient conceptual frameworks of intersectionality, minority stress, lived experiences, stigma, and resilience, palliative care providers are well positioned to create inclusive and affirmative healthcare practices and environments that will bridge the gap of the disparities in healthcare experienced by the LGBTQ population. This section provides recommendations for these strategies in affirming commitment to holistic, culturally humble, compassionate high-quality palliative care. This is a compilation of resources from various studies[47,78] and complemented by anecdotal experiences. Moreover, though these strategies are applicable to both LGBTQ and non-LGBTQ population, some nuances in the approach have been highlighted.

Best Practice Strategies for ALL disciplines:

- Taking cultural competency courses and being trained in proper communication will be advantageous to establishing rapport and developing a collaborative and trusting relationship. Getting certified in continuing medical education courses and workshops boosts the competency training.[79]
- Collect SOGI at the first visit and on intake forms from the outset. A few examples of appropriate scripting are as follows: ‘How do you want to be called/addressed? What pronouns do you go by? How do you identify in terms of gender identity (e.g. male, female, non-binary, transgender, other) and sexual orientation (e.g. gay straight lesbian bisexual, pansexual, asexual, other)?’
- Avoid heteronormative assumptions and misconceptions toward patients and their caregivers. Take time out to apologize when the wrong name, pronoun, or false assumptions are used.
- Take time out to include both patients and families/caregivers in clinical visits and explore the support system.
- Clinical providers along with interprofessional team members can create an open and safe forum to discuss complex cases including LGBTQ issues to help improve care for future patients.

Best Practice Strategies for: Physicians, Nurse Practitioners, Physician Assistants

- Holistic approach to history taking and physical examination including psychosocial, mental, sexual health, and well-being

- Follow standards of care with an evidence-based approach on total pain and symptom management with considerations to sociocultural and mental health factors that may impact total pain control such as the LGBTQ population's experience of inadequate pain assessment and treatment access to opioids (e.g. insurance issues) and preconceived judgments on their lifestyles (e.g. substance use).
- Understanding the LGBTQ patient medical needs in the context of minority stress is essential in offering holistic approach.[80]
- Be proactive in referring patients and their families/caregivers to other members of the interprofessional palliative care team after the needs assessment. These may include but not limited to social workers, chaplains, psychologists, rehabilitation therapists, child life therapists, creative arts specialists, integrative therapists, and so on. when these resources are available.
- Engage patients and families/caregivers in ACP discussions and proper documentation.

Best Practice Strategies for: Social Workers, Grief Counselors

- Explore psychosocial history including support networks. Be sensitive to families of choice. Understanding the lived experiences and unique journeys is the foundation for inclusive care.[81]
- Assistance with patient and caregiver burnout as families of choice might not be recognized as partners in care even though they may directly provide care for the patient. Furthermore, they are at risk for disenfranchised grief.
- Assist in goals of care conversations including filling out of relevant forms such as HCP and living will.
- Assistance with funeral planning, disposition of remains, permanency planning, hospital visitation, custody of children, and so on.
- Optimal and appropriate use of psychodynamic therapies within the scope of social work expertise. Examples include biofeedback and cognitive behavioral therapy. These are standard therapies that are not only offered to cisgender and heterosexual patients but to all patients regardless of SOGI.
- Provision of anticipatory grief and bereavement services are two key palliative care strategies for patients, families, and caregivers. Disenfranchised grief and survivor guilt especially for families of choice are significant issues that need professional support.

Best Practice Strategies for: Chaplains and Spiritual Care Counselors

- Understanding the life story and assisting in life review may be therapeutic for patients and families. Involving families of choice and caregivers in comprehensive assessment of spiritual needs is necessary to provide holistic care.[78]

Exploring spirituality and spiritual journey when applicable can be helpful for patients and families/caregivers. Use of the FICA tool could prove useful. FICA stands for Faith, Importance, Community, and Address spirituality.[82] The LGBTQ population has been subjected to rejection and bias from faith-based communities and organizations that perpetuate mistrust toward healthcare systems affecting the provision of optimal pastoral care for those interested in it. Understanding different coping strategies practiced by patients can allow the chaplain to consider them when offering management strategies. In addition, positive coping strategies and resilience should be explored as well.[21,22]

- May use Chochinov's Dignity Question: 'What should I know about you to help me provide the best care for you?'[83]

Best Practice Strategies for: Hospice and Palliative Care Organizations/Institutions

- Implementing policies against discrimination and bias while keeping up-to-date with expanded legal protections conveys an affirming message of support to all LGBTQ patients and employees.
- Identification, assessment, and management of unconscious bias using tools that will allow to capture this data in order to address barriers to diversity, equity, and inclusion.
- Mandatory cultural competency training for all providers and staff with opportunities for continuing medical education is vital to all-inclusive palliative and hospice care. The creation of a standard LGBTQ educational curriculum with ongoing evidence-driven revisions should be part of this cultural competency training. This could be available online for easy access by staff. In addition, opportunities for certification and recertification should be part of professional growth for all providers.
- Standardization and normalization of SOGI data collection allows everyone to be sensitive to an LGBTQ individual's personhood and creates a trusting relationship with the provider.

- Having internal resources to safeguard and address complaints and concerns toward outright discrimination and prejudice on patients and staff is an advantageous step impacting meaningful change toward welcoming environment.
- An investment in research studies regarding the palliative care needs and preferences for the care of LGBTQ patients should be carried out given that there are existing gaps in addressing them.
- A collaborative partnership with local, national, and international hospice and palliative care organizations should be forged to unify standards of medical care. Examples include the American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, and the National Hospice and Palliative Care Organization.
- Use of visible indicators in offices, hospitals, clinics, and other health care settings that promote a welcoming environment. These include rainbow flags, LGBTQ-related brochures, magazines, and so on.
- Healthcare organizations can also participate in open-access registries that monitor quality metrics pertaining to culturally competent LGBTQ patient care and receive accreditation for their strong efforts in advocating for this vulnerable population.

Palliative care considerations in special populations (minority within a minority population)

This section aims to provide an overview of the palliative care considerations in special LGBTQ adult populations to include the older adults, people with HIV/AIDS, and the TGNC population, all of which have unique needs and concerns that should be taken into account when providing high-quality palliative and hospice care. These groups are truly minorities within minorities, having to face multiple and intersectional layers of internal and external stressors, stigmas, and prejudices leading to significant physical and mental health outcomes.

Older adult population

In general, the aging health concerns of the LGBTQ population exist in a continuum from pre-hospital to hospital and post-acute care including palliative and hospice care. Much like their younger counterparts, older LGBTQ adults have multiple intersectional identities, minority stressors, and experiences of stigma that render them vulnerable to disproportionate healthcare access. The disability that comes with chronic and serious illness impacts which care settings they are eligible for. A key palliative care consideration is goal-concordant medical care in the appropriate care setting such as home or facility.[84] Institutionalized older adults have expressed concerns about how they might be treated by other residents and staff.[85] The desired visibility and presentation of older patients consistent with their preferred gender expression or as a manifestation of a specific stage in medical transition (e.g. TGNC) can draw attention and make them easy targets for further stigma and abuse while already living with serious illness.[85] Moreover, care providers might not be properly trained to advocate for and provide safety nets for them. An important affirmative strategy is the organization of support groups with a large network of allies and advocates. The literature is clear that there is some form of abuse that occur in long-term care facilities such as the lack of SOGI recognition and not honoring ACP documents.[85] Organizations should step up and institute non-discriminatory policies and practices in place. When geriatric LGBTQ patients experience serious illness, documentation of ACP discussions should take place as early as possible. It is not surprising that the care preferences could be reframed around quality of life rather than life-extending therapies. Rawlings found that SGM patients are at high risk for disparate persecution and devaluation.[86] Therefore, ACP is a top priority, and immediate designation of a HCP (e.g. friend, family of choice) could not be overlooked. This is further supported by the Metlife study that affirmed the role of informal caregiving to another ailing SGM person.[87] That said, older LGBTQ adults have developed affirmative and protective strategies as a result of resiliency and robustness built over decades of oppression and discrimination in order to survive and live their authentic selves.[88,89] This crisis competence is observed in a 2015 Fredriksen-Goldsen and colleagues' study on a multidimensional Resilience Framework in which the findings point to the interconnections between successful aging, physical and mental health outcomes, and social connectedness within the context of the unique experiences of older LGBTQ adults (e.g. positive sexual identity and lifetime victimization). Physical activity, leisure activity, and substance non-use were related to better mental and physical health-related quality of life.

In addition, a better positive self-evaluation led to better mental health.[44] Several studies have also reported resiliency and successful coping among older gay men with HIV. Strength-based resources observed include self-acceptance, optimism, will to live, self-management, relational living, and independence. Furthermore, other stress buffers include gay community supports, knowledge on HIV/AIDS, and other self-care activities.[90]

HIV disease

Historically, the first experiences on the provision of hospice and palliative care in the LGBTQ population started in the 1980s at the height of the HIV-AIDS epidemic and before the introduction of the anti-retroviral therapy (ART).[78] Much of the research studies centered around the care of gay men and their caregivers who had to endure the stigma around how they were viewed and managed medically. The barriers to care included estrangement from families, lack of respect by providers on chosen families to make medical decisions even if clearly appointed by patient, visitation restrictions on the chosen families and caregivers, discrimination by health care staff, variable levels of SOGI disclosure, strong mistrust in faith-based organizations who frowned on their lifestyles, and lack of legal protections.[78,91] Collectively, these spurred the need for inclusive and culturally competent palliative care, caregiver support, bereavement services, and creation of protective policies. The general palliative care strategies for the LGBTQ adult outlined previously mirror the approach to palliative care for the LGBTQ adult with HIV/AIDS. However, there are some nuances given that there are two stigmatizing dimensions affecting this population with their set of upheavals and impact. It is important to note that with the advent of ART, HIV patients are living longer and the disease is no longer considered terminal. Having said that, this immunodeficiency syndrome now invariably affects the life course of the individual who may be faced with tremendous symptom burden with risk for advancement of disease if not treated.[92]

Recommendations on Best Practices for LGBTQ Adults with HIV/AIDS

- Collaboration with HIV experts and primary care providers is critical to ensuring seamless collaboration with the palliative and hospice care providers.
- For comprehensive planning, focus on quality-of-life indicators such as pain and symptom distress, illness trajectory and future planning, overall well-being and mental health, addiction, and suicide risk, among others.
- Engage in early advance planning discussions by completing advance directive forms, for example, healthcare proxy and living will. Completion of a MOLST/POLST form is prudent as well. Two older studies showed that gay and bisexual men were more likely to have a prior directive or more likely to discuss EOL care.[93,94]
- Regarding continuation or cessation of anti-retroviral therapy (ART), this becomes a shared decision-making approach depending on overall goals of care in the setting of disease trajectory and complications.

TGNC population

TGNC patients continue to be understudied in the palliative care literature. Lambda Legal survey showed a high level of mistrust by this population toward the healthcare systems at large.[26] Harding's systematic review revealed that the presence of family and other support systems was important for emotional support and medical decision making even though a heteronormative assumption was observed among healthcare providers.[95] The study also emphasized the importance of quality of life more than life-sustaining therapies at the end of life.[96] Regardless, TGNC patients have reported concerns about consistent, respectful, and sensitive treatment approach especially in the areas of wound and genital care even in hospice and palliative care settings. There is no universal standard regarding continuation or cessation of hormonal therapy in relation to serious illness and the dying trajectory. The current practice hinges on shared decision making between patients and providers while taking into consideration the risks and benefits to hormonal use and quality of life metrics. In addition, the provision of palliative and hospice care in various settings poses tangible challenges toward SOGI use and physical care that might expose further vulnerabilities when faith-based organizations take the lead in their care. As a result, TGNC older adults are pressured to hide their authentic selves and not live openly about who they are.[68] There is a wide gap in the literature regarding EOL and post-mortem care for this population. There is grave concern that their SOGI and other preferences for care will be ignored.[81] Use of the names assigned at birth might be engraved upon burial. Their chosen families might not get recognized in burial planning. Moreover, when after their demise if they become a coroner's responsibility, appropriate SOGI might not be reflected on their death certificates and autopsy results. The National Resource Center on LGBT Aging is a good resource to look into documents and videos detailing wills, social security benefits, and funeral directives.[63]

Recommendations on Best Practice Strategies for Palliative Care Clinicians

- Clinicians can provide holistic care by understanding and validating the lived experiences of TGNC patients. Chochinov's 'Dignity Question' is always an effective tool to start the conversation on their lived experiences.
- As described previously, during the physical examination of TGNC patients, it is respectful for the clinician to obtain permission before examining any body part; asking the patient to take the lead in sharing how they name their body parts; providing a thorough explanation of the rationale for the physical exam and any concerning findings that warrant further investigation; and collaborating on the next steps in a tailored comprehensive plan of care.
- Sexual issues in palliative care should be explored inasmuch as other physical needs are being addressed.[97,98]
- It is advisable to closely collaborate with the primary care providers and endocrine specialists who are managing the hormonal use of TGNC patients. Being familiar with the World Professional Association of Transgender Health (WPATH) and University of California San Francisco (UCSF) standard of medical care for TGNC patients may be helpful for the palliative care specialists to integrate current medical therapies with symptom management.
- ACP should be done as soon as possible. Filling out forms such as HCP, living will, and MOLST is necessary and best done while healthier.
- Interprofessional support should be part of the care from the outset to explore psychosocial, spiritual, and bereavement needs.
- Planning around future finances, burial services, adoption/custody issues for TGNC patients with children, and so on should be addressed as soon as possible.[96]

Conclusion

The provision and delivery of high-quality palliative, hospice, and EOL care starts with an understanding of the cultural framework that has shaped the life course of the LGBTQ population and the minorities within minorities subgroups. The long-standing prejudice, stigma, discrimination, and oppression have resulted in delays and avoidance in seeking medical care, disparate physical and mental health outcomes, and mistrust with the healthcare system as a whole. The barriers to comprehensive palliative care include gaps in competency training for providers, paucity in research studies, variable resource allocation, financial constraints, and non-protective regulatory policies and practices. There are key strategies to mitigate these barriers while providing affirmative and inclusive care toward SGM patients that can create a therapeutic alliance, improved patient and caregiver satisfaction, enhanced quality of life, and overall well-being. A holistic team-based approach coupled with empathic communication and non-judgmental mind-set are fundamental steps that offer an effective, successful, and trusting relationship to both patients and caregivers. There is renewed hope with the Biden administration that legal protections for the healthcare of the LGBTQ population in the United States will be enforced and expanded to affirm commitment for universal healthcare for all people irrespective of their backgrounds.

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References

1. https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic (accessed 2 July 2021).
2. Choi SK and Meyer IL. *LGBT aging: a review of research findings, needs, and policy implications.*

Los Angeles, CA: The Williams Institute, UCLA School of Law, 2016.

3. Snyder JE. Trend analysis of medical publications about LGBT persons: 1950-2007. *J Homosex* 2011; 58: 164–188.
4. Institute on Medicine. *The health of lesbian, gay, bisexual, and transgender people: building a foundation for better understanding*. Washington, DC: The National Academies Press, 2011.
5. Fredriksen-Goldsen KI, Kim HJ, Bryan AEB, *et al*. The cascading effects of marginalization and pathways of resilience in attaining good health among LGBT older adults. *Gerontologist* 2017; 57(Suppl. 1): S72–S83.
6. Yarns BC, Abrams JM, Meeks TW, *et al*. The mental health of older LGBT adults. *Curr Psychiatry Rep* 2016; 18: 60.
7. GLAAD. *Accelerating acceptance 2019: a survey of American acceptance and attitudes toward LGBTQ Americans*. New York: GLAAD, 2019.
8. https://www.glsen.org/sites/default/files/LGBTQ-History-Timeline-References.pdf (accessed 2 July 2021).
9. Nadal KL, Davidoff KC and Davis LS. A qualitative approach to intersectional microaggressions: understanding influences of race, ethnicity, gender, sexuality, and religion. *Qual Psychol* 2015; 2: 147–163.
10. Bowleg L. The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *Am J Public Health* 2012; 102: 1267–1273.
11. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull* 2003; 129: 674–697.
12. Aldwin CM, Igarashi H, Gilmer DF, *et al*. *Health, illness, and optimal aging: biological and psychological perspectives*. 2nd ed. New York: Springer Publishing Company, 2013.
13. Witten TM. End of life, chronic illness, and trans-identities. *J Soc Work End Life Palliat Care* 2014; 10: 34–58.
14. Herek GM. A nuanced view of stigma for understanding and addressing sexual and gender minority health disparities. *LGBT Health* 2016; 3: 397–399.
15. Chidiac C and Connolly M. Considering the impact of stigma on lesbian, gay, and bisexual people receiving palliative and end of life care. *Int J Palliat Nurs* 2016; 22: 334–340.
16. Meyer IH. Resilience in the study of minority stress and health of sexual and gender minorities. *Psychol Sex Orient Gender Divers* 2015; 2: 209–213.
17. Smith MS and Gray SW. The courage to challenge: a new measure of hardiness in LGBT adults. *J Gay Lesbian Soc Serv* 2009; 21: 73–89.
18. Colpitts E and Gahagan J. The utility of resilience as a conceptual framework for understanding and measuring LGBTQ health. *Int J Equity Health* 2016; 15: 60.
19. McConnell EA, Janulis P, Phillips G 2nd, *et al*. Multiple minority stress and LGBT community resilience among sexual minority men. *Psychol Sex Orientat Gend Divers* 2018; 5: 1–12.
20. Singh AA and McKleroy VS. 'Just getting out of bed is a revolutionary act': the resilience of transgender people of color who have survived traumatic life events. *Eur Phys Educ Rev* 2011; 17: 34–44.
21. Bonanno GA, Westphal M and Mancini AD. Resilience to loss and potential trauma. *Annu Rev Clin Psychol* 2011; 7: 511–535.
22. Smith BW, Tooley EM, Christopher PJ, *et al*. Resilience as the ability to bounce back from stress: a neglected personal resource? *J Posit Psychol* 2010; 5: 166–176.
23. Witten TM. It's not all darkness: robustness, resilience, and successful transgender aging. *LGBT Health* 2014; 1: 24–33.
24. Meyer I. Identity, stress, and resilience in lesbians, gay men, and bisexuals of color. *Couns Psychol* 2010; 38: 1–7.
25. Grasso C, Goldhammer H, Brown RJ, *et al*. Using sexual orientation and gender identity data in electronic health records to assess for disparities in preventive health screening services. *Int J Med Inform* 2020; 142: 104245.
26. When health care isn't caring? Lambda Legal Survey on LGBT people and people living with HIV, https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf (2010, accessed 26 August 2021).
27. Sabin JA, Riskind RG and Nosek BA. Health care providers implicit and explicit attitudes toward lesbian women and gay men. *Am J Public Health* 2015; 105: 1831–1841.
28. James SE, Herman JL, Rankin S, *et al*. *The report of the 2015 US transgender survey* Washington, DC: National Center for Transgender Equality, 2016.
29. Carter PL and Reardon SF. *Inequality matters*. New York: William T. Grant Foundation,

https://ed.stanford.edu/sites/default/files/inequalitymatters.pdf (September 2014, accessed 19 March 2021).

30. MacCartney D and Fuwa M. *Intersecting inequality: the effects of race, class, gender, and sexual orientation*. Princeton, NJ: Princeton University, http://paa2006.princeton.edu/papers/61138 (2006, accessed 2 July 2021).
31. Veenstra G. Race, gender, class, and sexual orientation: intersecting axes of inequality and self-rated health in Canada. *Int J Equity Health* 2011; 10: 3.
32. Balsam KF, Molina Y, Beadnell B, *et al*. Measuring multiple minority stress: the LGBT People of Color Microaggressions Scale. *Cultur Divers Ethnic Minor Psychol* 2011; 17: 163–174.
33. Williams D and Mohammed S. Discrimination and racial disparities in health: evidence and needed research. *J Behav Med* 2009; 32: 20–47.
34. Dai H and Hao J. Sleep deprivation and chronic health conditions in sexual minority adults. *Behav Sleep Med* 2017; 17: 254–268.
35. Emlet CA. Social, economic, and health disparities among LGBT older adults. *Generations* 2016; 40: 16–22.
36. Espinoza R. *Out and visible: the experiences and attitudes of LGBT older adults, ages 45-75*. New York: Services and Advocacy for GLBT Elder, 2014.
37. Wallace S, Cochran S, Durazo E, *et al*. *The health of aging lesbian, gay, and bisexual adults in California*. Los Angeles, CA: UCLA Center for Health Policy Research, 2011.
38. Fredriksen-Goldsen KI, Kim HJ, Barkan SE, *et al*. Health disparities among lesbian, gay, and bisexual older adults: results from a population-based study. *Am J Public Health* 2013; 103: 1802–1809.
39. Fredriksen-Goldsen KI. Resilience and disparities among lesbian, gay, bisexual, and transgender older adults. *Public Policy Aging Rep* 2011; 21: 3–7.
40. Kenagy GP. Transgender health: findings from two needs assessment studies in Philadelphia. *Health Soc Work* 2005; 30: 19–26.
41. Lindstrom M and Rosvall M. Sexual identity and low leisure-time physical activity: a population based study. *Public Health* 2020; 182: 77–79.
42. Galloza J, Castillo B and Micheo W. Benefits of exercise in the older population. *Phys Med Rehabil Clin N Am* 2017; 28: 659–669.
43. Flenar DJ, Tucker CM and Williams JL. Sexual minority stress, coping, and physical health indicators. *J Clin Psychol Med Settings* 2017; 24: 223–233.
44. Fredriksen-Goldsen K, Kim HJ, Shiu C, *et al*. Successful aging among older adults: physical and mental health-related quality of life by age group. *Gerontologist* 2015; 55: 154–168.
45. Haider AH, Schneider EB, Kodalek LM, *et al*. Emergency departmental query for patient-centered approaches to sexual orientation and gender identity: the EQUALITY Study. *JAMA Intern Med* 2017; 177: 819–828.
46. Acquaviva K. *LGBTQ-inclusive hospice and palliative care: a practical guide to transforming professional practice*. New York: Harrington Park Press, 2017.
47. Cloyes KC, Hull W and Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, transgender cancer patients and their caregivers. *Semin Oncol Nurs* 2018; 34: 60–71.
48. Witten TM. Graceful exits: intersection of aging, transgender identities, and the family/community. *J GLBT Fam Stud* 2009; 5: 35–61.
49. Stein GL and Bonuck KA. Attitudes on end-of-life care and advance care planning in the lesbian and gay community. *J Palliat Med* 2001; 4: 173–190.
50. Aging with dignity: five wishes, https://agingwithdignity.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2 (accessed 13 March 2021).
51. POLST: advance care planning for the seriously ill, http://polst.org/wp-content/uploads/2018/01/2013.09.26_Final-POLST-Article.pdf (accessed 2 July 2021).
52. MOLST: medical orders for life sustaining treatment, https://www.health.ny.gov/forms/doh-5003.pdf (accessed 13 April 2021).
53. Cartwright C, Hughes M and Lienert T. End-of-life care for gay, lesbian, bisexual, and transgender people. *Cult Health Sex* 2012; 14: 537–548.
54. Hughes M and Cartwright C. LGBT people's knowledge of and preparedness to discuss end-of-life care planning options. *Health Soc Care Community* 2014; 22: 545–552.
55. Drescher J. Queer diagnoses: parallels and contrasts in the history of homosexuality, gender variance, and the diagnostic and statistical manual. *Arch Sex Behav* 2010; 39: 427–460.

56. Drescher J. Out of DSM: depathologizing homosexuality. *Behav Sci* 2015; 5: 565–575.
57. Pillard R. From disorder to dystonia: DSM-II and DSM-III. *J Gay Lesbian Ment Health* 2009; 13: 82–86.
58. American Psychiatric Association. *Gender dysphoria*. Washington, DC: American Psychiatric Association, https://www.psychiatry.org/patients-families/gender-dysphoria (2013, accessed 2 July 2021).
59. D'Augelli AR, Grossman AH, Hershberger SL*, et al*. Aspects of mental health among older lesbian, gay, and bisexual adults. *Aging Ment Health* 2001; 5: 149–158.
60. Wight RG, LeBlanc AJ, Meyer IH*, et al*. Internalized gay ageism, mattering, and depressive symptoms among midlife and older gay-identified men. *Soc Sci Med* 2015; 147: 200–208.
61. Grant JM, Mottet LA, Tanis J*, et al*. *Injustice at every turn: a report of the national transgender discrimination survey*. Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011.
62. Cochran SD, Grella CE and Mays VM. Do substance use norms and perceived drug availability mediate sexual orientation differences in patterns of substance use? Results from the California Quality Life Survey II. *J Stud Alcohol Drugs* 2012; 73: 675–685.
63. Pantalone DW, Bimbi DS and Parsons JT. Motivations for the recreational use of erectile enhancing medications in urban gay and bisexual men. *Sex Transm Infect* 2008; 84: 458–462.
64. McCabe SE, West BT, Hughes TL*, et al*. Sexual orientation and substance abuse treatment utilization in the United States: results from a national survey. *J Subst Abuse Treat* 2013; 44: 4–12.
65. Fredriksen-Goldsen KI, Emlet CA, Kim HJ*, et al*. The physical and mental health of lesbian, gay male, and bisexual (LGB) older adults: the role of key health indicators and risk and protective factors. *Gerontologist* 2013; 53: 664–675.
66. Monin JK, Mota N, Levy B*, et al*. Older age associated with mental health resiliency in sexual minority US Veterans. *Am J Geriatr Psychiatry* 2017; 25: 81–90.
67. Stein GL, Berkman C, O'Mahony S*, et al*. Experiences of lesbian, gay, bisexual, and transgender patients and families in hospice and palliative care: perspectives of the Palliative Care Team. *J Palliat Med* 2020; 23: 817–824.
68. Arthur DP. Social work practice with LGBT elders at end of life: developing practice and clinical skills through a cultural perspective. *J Soc Work End Life Palliat Care* 2015; 11: 178–291.
69. Gendron T, Maddux S, Krinsky L*, et al*. Cultural competence training for healthcare professionals working with LGBT older adults. *Educ Gerontol* 2013; 39: 454–463.
70. Durso LE. Data move us closer to full equality by speaking for those who cannot: advocating for LGBT older adults. *Am J Public Health* 2017; 107: 1219–1220.
71. Cahill SR. Research and policy change to improve healthcare and elder services for LGBT older adults. *LGBT Health* 2017; 4: 381–383.
72. https://www.washingtonpost.com/religion/2021/03/16/equality-act-fairness-for-all-religious-liberty-lgbtq-lgbt-biden/ (accessed 2 July 2021).
73. https://www.hrw.org/news/2020/06/15/us-supreme-court-ruling-victory-lgbt-workers# (accessed 2 July 2021).
74. Fredriksen-Goldsen K, Siu C, Kim HJ*, et al*. *At risk and underserved: LGBTQ older adults in Seattle/King County, Findings from aging with pride*. Seattle, WA: University of Washington, 2015.
75. Johnson L, Shipperd JC and Walton H. The psychologist's role in transgender specific care with US veterans. *Psychol Serv* 2016; 13: 69–76.
76. Daniel H and 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: 135–148.
77. Puckett JA, Cleary P, Kinton R*, et al*. Barriers to gender affirming care for transgender and gender non-conforming individuals. *Sex Res Soc Policy* 2018; 15: 48–59.
78. Maingi S, Bagabag AE and O'Mahony S. Current best practices for sexual and gender minorities in hospice and palliative care settings. *J Pain Symptom Manage* 2018; 55: 1420–1427.
79. Foronda G, Baptiste DL, Reinholdt MM*, et al*. Cultural humility: a concept analysis. *J Transcult Nurs* 2016; 27: 210–217.
80. Hatzenbuehler ML and Pachankis JE. Stigma and minority stress as social determinants of health among lesbian, gay, bisexual, and transgender youth. *Pediatr Clin North Am* 2016; 63: 985–997.
81. Diewald M and Mayer KU. The sociology of the life course and life span psychology: integrated paradigm or complementing pathways? *Adv Life Course Res* 2009; 14: 5–14.

82. Borneman T, Ferrell B and Puchalski C. Evaluation of the FICA tool for spiritual assessment. *J Pain Symptom Manage* 2010; 40: 163–173.
83. Chochinov HM, McClement S, Hack T, *et al.* Eliciting personhood within clinical practice: effects on patients, families, and health care providers. *J Pain Symptom Manage* 2015; 49: 974–980.
84. Adams M and Tax AD. Assessing and meeting the needs of LGBT older adults via the Older Americans Act. *LGBT Health* 2017; 4: 389–393.
85. *LGBT older adults in long-term care facilities: stories from the field*. SAGE, Lambda Legal, and National Senior Citizens Law Center Collaboration, https://www.diverseelders.org/resource/lgbt-older-adults-in-long-term-care-facilities-stories-from-the-field/ (2011, accessed 13 March 2021).
86. Rawlings D. End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals: case study. *Int J Palliat Nurs* 2012; 1: 29–34.
87. Metlife Mature Market Institute. Still out, still aging: the Metlife study of lesbian and gay baby boomers, https://www.tandfonline.com/doi/full/10.1080/15504280903472949?scroll=top&needAccess=true (2010, accessed 2 July 2021).
88. de Vries B, Gutman G, Humble A, *et al.* End-of-life preparations among LGBT older Canadians: the missing conversations. *Int J Aging Hum Dev* 2019; 88: 358–379.
89. 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: 1–13.
90. Van Wagenen A, Driskell J and Bradford J. ‘I’m still raring to go’: successful aging of lesbian, gay, bisexual, and transgender older adults. *J Aging Stud* 2013; 27: 1–14.
91. Biller R and Rice S. Experiencing multiple losses of persons with AIDS: grief and bereavement issues. *Health Soc Work* 1990; 15: 283–290.
92. Simms V, Higginson I and Harding R. Integration of palliative care throughout HIV disease. *Lancet Infect Dis* 2012; 12: 571–575.
93. Teno J, Fleishman J, Brock DW, *et al.* The use of formal prior directives among patients with HIV-infected diseases. *J Gen Intern Med* 1990; 5: 490–494.
94. Curtis JR, Patrick DL, Caldwell E, *et al.* The quality of patient-doctor communication about end-of-life care: a study of patients with advanced AIDS and their primary care clinicians. *AIDS* 1999; 13: 1123–1131.
95. Harding R, Epiphaniou E and Chidgey-Clark J. Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. *J Palliat Med* 2012; 15: 602–611.
96. Porter KE, Oala CR and Witten TM. Transgender spirituality, religion, and successful aging: findings from the Trans Metlife Survey. *J Relig Spiritual Aging* 2012; 25: 112–138.
97. Shell JA. Sexual issues in the palliative care population. *Semin Oncol Nurs* 2008; 24: 131–134.
98. Griebling TL. Sexuality and aging: a focus on lesbian, gay, bisexual, and transgender (LGBT) needs in palliative and end of life care. *Curr Opin Support Palliat Care* 2016; 10: 95–101.

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