

## Review

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# Hospice and Palliative Care for Older Lesbian, Gay, Bisexual and Transgender Adults: The Effect of History, Discrimination, Health Disparities and Legal Issues on Addressing Service Needs

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### ABSTRACT

The acronym LGBT refers to groups of people who are lesbian, gay, bisexual and transgender, groups historically marginalized, mistreated, ignored by society and the health care delivery systems, including hospice and palliative care services. The purpose of this literature review was to explore the characteristics, history, health and health care disparities, social support systems and legal issues of LGBT persons with a particular focus on older adults, end-of-life care, and ways in which hospice and palliative care organizations can better meet their needs. Despite the fact that sound enquiry is needed to improve health-related outcomes, what little research has been done with LGBT adults in general and, specifically, with older LGBT adults, has focused mainly on HIV/AIDS and other sexually transmitted diseases. As a social minority, LGBT persons are more likely to experience economic insecurity, lack health insurance, experience invisibility, and be victimized and mistreated. This is especially true of older LGBT adults who grew up in a less tolerant era when sexual minorities were criminalized and stigmatized as pathological, sinful, and immoral. Their minority status has led to health issues and health care disparities, and requires health professionals to consider systems in a way that redefines family, addresses legal concerns, and responds with options of care unlike those of their heterosexual counterparts. With recent changes in societal attitudes and some progress in addressing legal concerns, hospice and palliative care organizations now have a unique opportunity to lead the health care community by pioneering culturally sensitive and appropriate methods to better serve this population.

**KEYWORDS:** Lesbian, Gay, Bisexual and Transgender (LGBT); Health disparities; Hospice; Older adults; Palliative care; End-of-life; Cultural sensitivity.

**ABBREVIATIONS:** LGBT: Lesbian, Gay, Bisexual and Transgender; DHHS: Department of Health and Human Services; ACA: Affordable Care Act; DOMA: Defense of Marriage Act; SAGE: Services and Advocacy for GLBT Elders.

### INTRODUCTION

The acronym LGBT refers to groups of people who are lesbian, gay, bisexual and transgender. Although, the abbreviation suggests a homogeneous group, it includes a wide range of people<sup>1</sup> in part because it combines sexual orientation with gender identity.<sup>2</sup> Sexual orientation is the “enduring emotional, romantic, sexual or affectional attraction to another person”.<sup>3</sup> For

gay men, this attraction is primarily to men, and for lesbians, this attraction is primarily to women. Gender identity is a person's self-perception as a man or woman. Sexual identity, in contrast refers to the cognitive and emotional meaning one attaches to expressions of sexuality in all of its forms, from fantasy to attraction and value judgements to behaviour. Although this means that sexual identity and sexual orientation are inextricably bound together, it would be a mistake to assume that the two are necessarily congruent or, if they are, that they would remain that way over time.<sup>3</sup> In other words, there is no reason to assume that sexual orientation, sexual identity, and gender identity are static; as environments change, individuals, too, may change over their life course.<sup>3</sup> Thus, each person of the LGBT group is a distinct individual with unique experiences that are shaped by multiple factors such as race/ethnicity, socioeconomic status, geographical location and age, not just sexual orientation.<sup>4,5</sup>

Sex, gender, gender identity, and sexual orientation are the terms around which we organize our scientific exploration and social thinking. One's sex is seen as either male or female, characterized by the biological evidence of obvious genitalia and chromosome pair. Gender is purely a social construct and denotes a role-based distinction between men and women. From an institutional perspective we assume that being male should synchronize with behaving the way "a man" is expected to behave. Similarly, designated females are expected to act like women. This expectation is so locked into our organizational structures that forms and questionnaires are typically restricted to checking off one of two choices as if a third choice were almost unthinkable. This questionable binary assumption is further confounded by science's inconsistent use of the terms sex and gender, often treating them as interchangeable variables.<sup>6</sup>

Data on the size of the LGBT population are limited. In part, this is due to a socially-constructed ambivalence about formally recognizing this population as a unique group. In the US, institutionalized tracking of this large and diverse population began with the 1990 Census that included a module on same-sex, unmarried partners.<sup>7</sup> Despite recent modest political gains, such as the legal right to marry in many states, prevailing social attitudes continue to assume sex-gender-sexual identity congruence and favour heterosexual behaviour making accurate census data of lesbian, gay, bisexual and transgendered population difficult to obtain.

Estimates indicate approximately 3.4% of the US population identify as members of LGBT communities.<sup>8</sup> Approximately 3% of adults self-identify as LGB<sup>9</sup> persons including about 3 million older adults.<sup>10</sup> An estimated 1.5 to 7 million Baby Boomers, the first generation to be 'out', fall within this category.<sup>8</sup> In spite of these significant numbers, little research has been done with LGBT adults in general and, specifically, with older LGBT adults.<sup>11</sup> The research that has been done has focused mainly on HIV/AIDS and other sexually transmitted diseases.<sup>11,12</sup>

This makes sexual minorities one of the most understudied and consequently underserved groups in health disparities research.<sup>2</sup> A history of perceived and endured social stigma attached to being a sexual minority ties into a reluctance of some, particularly older adults, to self-identify as LGBT, resulting in their absence from research and its findings.<sup>11</sup> And yet, research suggests that most LGBT adults will provide information on sexual orientation and gender identity if told why the information is needed and if privacy and confidentiality are assured.<sup>3</sup> The small size of this population relative to the total population adds to the difficulty and expense of recruiting participants into research studies.<sup>5</sup> And yet, good, sound research is needed to discover mechanisms to improve health and reduce health disparities and inequalities for sexual minorities.<sup>3</sup> The IOM<sup>5</sup> has stated that data on sexual orientation and gender identity need to be collected regularly within all national studies. In response, several government agencies have, according to a recent Department of Health and Human Services (DHHS)<sup>13</sup> report, taken steps to identify and correct health-related gaps, including services for LGBT seniors.

The purpose of this literature review is to explore the characteristics, history, health and health care disparities, social support systems and legal issues of LGBT persons with a particular focus on older adults. This review will also explore factors related to end-of-life planning and how hospice and palliative care organizations can meet the needs of this population at the end of life.

## METHODS

One of the challenges of this review was the lack of a universally-accepted acronym for those who self-identify as LGBT. Depending on region, agency, or perhaps even whim of the research team, a variety of acronyms have been used: LGB; LGBT; LGBTQ (the Q referring to queer); LGBTQQ (the second Q referring to questioning); LGBTQU (the U referring to undecided); LGBTQI (the I referring to intersexed); and flipping the script, GLBT. In this literature review, the following search terms were used in addition to the acronyms listed: lesbian, gay, homosexual, bisexual, transgendered, sexual orientation, sexual minority, sexual preference, health, health disparities, hospice, palliative care, end-of-life, social support, legal issues, elder, older adult, aging and gerontology.

The next step was to identify target databases broad enough to draw a relatively complete profile of the LGBT population and end-of-life needs; these included EBSCO, PubMed, Medline, PsychInfo, Socindex, Social Science Index, and JS-TOR. Inclusion criteria included publications must be scholarly, peer-reviewed journal articles, reports and books, published within the last ten years, which focused on issues directly or indirectly affecting the health of individuals who identify as LGBT persons in the US. This included general characteristics and experiences, health and health care disparities, social sup-

port systems, and legal issues. An exception was made for historical data provided by earlier research. Geographical location was limited to studies done in the US as the ultimate goal was to discover ways to improve hospice and palliative care practices within this country. However, the findings provide understandings for other countries who share parallel issues affecting the health of the LGBT community.

Sixty studies were systematically and comprehensively reviewed to generate a cohesive understanding about the history, health and health care disparities, social support, legal issues, and end-of-life attitudes and beliefs of sexual minorities through analysis of both the knowledge and the context in which it was produced.<sup>14</sup>

## LITERATURE REVIEW

LGBT persons are part of every community; many live in poverty and, prior to the Affordable Care Act (ACA) of 2010 in the United States, had little or no health insurance, all of which increase the risk for poor health outcomes.<sup>4</sup> Although it remains unclear what, if any, impact the ACA will have for LGBT elders, the law did incorporate language to allow for more options and benefits for sexual minorities.<sup>15</sup> Nonetheless, a 2013 study found that a third of LGBT persons surveyed were not insured, with about two thirds of them having been uninsured for two or more years.<sup>16</sup>

As a group, LGBT persons are more likely to experience economic insecurity, especially if they are rural and female.<sup>8</sup> A lifetime of discrimination, less likelihood of having employer sponsored pensions and health insurance, not being covered under their partner's plan, having to pay more for health care even with insurance, and denial of most survivor and death benefits, all increase the likelihood of financial and health problems in later life.<sup>8</sup> Older LGBT persons are twice as likely as heterosexuals to live alone<sup>17,18</sup> and four times more likely to be childless<sup>18</sup> which impacts their support networks. Policies on aging have long ignored the needs of older LGBT adults and, as a result, older LGBT persons experience institutionalized discrimination *via* unequal access to benefits and services.<sup>17</sup> For example, agencies serving the elderly tend to be less accepting of older LGBT adults than the health care system in general.<sup>19</sup> One of the main obstacles to changing public policy has been heterosexist public opinion.<sup>17</sup> This heterosexist attitude outside the LGBT community is further complicated by an ageist attitude within the LGBT community which tends to value beauty and youthfulness, not age, and is more ageist than society in general.<sup>19</sup>

From a social perspective, LGBT persons constitute a minority group. As such, they are not recognized as being legitimate and equal; they are marginalized, discriminated against, and may experience violence or invisibility.<sup>20</sup> Discrimination against LGBT persons is lifelong and permeates all aspects of life.<sup>21</sup> Victimization of LGBT people may occur at multiple levels beyond

sexual orientation, including cultural differences, the impact of living within a heterosexist culture, and indirect discrimination suffered by friends, family members and loved ones.<sup>22</sup>

The literature explains issues of minority stress of the LGBT population. Living within the societal prejudice of a heterosexist society is associated with negative mental and physical health outcomes.<sup>23</sup> A unique aspect of minority stress for LGBT persons is that sexual orientation is usually invisible; this leads to lack of sensitivity and inadvertent insensitivity from people unaware of a person's sexual orientation as well as overt discrimination.<sup>19,23</sup> LGBT people may be subject to ridicule, become targets for demeaning and derogatory slang and insensitive jokes, and have their personal morality and value as human beings questioned.<sup>23</sup> Prejudice may be internalized due to living within a culture in which a group is devalued; this may lead to an internal struggle to balance the need for equality with the need for peace and escape from public scrutiny and discrimination.<sup>23</sup> Striving for peace and escape may involve the practice of covering, "toning down a disfavored identity in order to fit into mainstream".<sup>24</sup> Some research considers homosexuality a master status, a status that overshadows all other statuses and defines who a person is.<sup>19,20</sup> Intersectionality theorists refute this and suggest that people, including those who self-identity as LGBT persons, have multiple intersecting marginalized statuses that are equally important.<sup>5</sup>

Today's older LGBT adults are unique because they grew up in a significantly less tolerant era.<sup>1</sup> It was common for older LGBT people to conceal their sexual identity and/or orientation and, thus, many experienced invisibility<sup>25</sup> or denied their nature and conformed for the sake of public acceptance. Their early socialization took place at a time when LGBT status was considered pathological, sinful, and immoral.<sup>20</sup> It was criminalized, stigmatized, and classified as a mental illness.<sup>20,26</sup> Many of today's older adults came of age before the gay rights movement, initiated by the June, 1969, Stonewall Rebellion<sup>27</sup> in which gay male and transgender patrons of the Stonewall Inn in Greenwich Village, New York City, took a stand against police harassment and refused to hide their sexual orientation.<sup>19,20</sup> Many older LGBT persons have experienced adverse psychosocial repercussions from the movement<sup>21</sup> that are different from their younger counterparts;<sup>19</sup> while the latter gained a public political identity, older adults now had to find ways to reconcile a new reality with years of enduring stigma and self-imposed isolation.<sup>27</sup> Therefore, it is important to keep the social context of discrimination and victimization experienced in early and later years in mind as possible links to mental health and disability problems in later life.<sup>20,26</sup>

Studies also show that older LGBT people are at an increased risk over the life course for interpersonal violence in intimate relationships, violence perpetrated by other LGBT people, and hate crimes.<sup>22</sup> Rates of victimization may be higher among those who are open about their sexual orientation.<sup>22</sup> Compound-

ing this vulnerability is the stress related to their social status as a minority group. Minority stress results from the incongruity between personal needs and experiences and the structure and morality of the dominant society or culture.<sup>20</sup> Lack of rights and marginalization within a society increases stress which can, in turn, add to physical and mental health problems.<sup>24</sup>

## HEALTH AND HEALTH CARE DISPARITIES

The United States is an aging society. As people live longer, they are more likely to experience chronic co-morbidities; the LGBT community has the added burden of poor health outcomes related to health disparities. The LGBT population has encountered, and continues to experience, disparities in health and health care. Healthy People 2020 defines health disparities as “differences in health outcomes for communities that have encountered systematic obstacles to health as a result of social, economic, and environmental disadvantage”.<sup>26</sup> For LGBT elders, economic problems and marginalization have both caused and resulted in health disparities.<sup>8</sup> For example, LGB and transgender persons are less likely than their heterosexual counterparts to have employer-based health insurance (77% and 51% vs 82%)<sup>8</sup> and far less likely to be covered under their partner’s health insurance.<sup>21</sup> This can lead to unmet health needs during the working years and earlier onset of chronic conditions. Lack of health insurance is mainly due to discriminatory employer practices and the absence of federal laws that prohibit discrimination based on sexual orientation.<sup>21,28</sup> Studies comparing the health status and prevalence of health conditions of heterosexual and LGBT adults have been inconclusive; some show more health problems among LGBT people such as diabetes, hypertension, disability, and mental health problems,<sup>8</sup> while others have found no differences in physical health but higher levels of disability and poor mental health.<sup>26</sup>

An additional barrier to accessing quality health care is lack of provider knowledge about LGBT populations.<sup>5</sup> Many LGBT people avoid the health care system due to fears of discrimination and poor treatment within the system.<sup>1</sup> Studies have revealed that six percent of physicians are uncomfortable caring for LGBT patients<sup>1</sup> and that a small but important minority of medical students, especially male students under the age of 25, held a narrow view of male identity and were uncomfortable with gay male behaviour.<sup>29</sup>

A 2009 national study by Lambda Legal<sup>30</sup> found that discrimination and barriers to care prevalent among LGBT populations included: refusal of care due to sexual orientation, gender identity, or HIV status; care delivered without touching the patient or with the use of excessive precautions; harsh or abusive language; blame for health status; and physical roughness or abuse. The findings of this study probably underestimate the problems because LGBT study participants had health insurance and relatively high socioeconomic status.

Some argue that health risks are not caused by being an LGBT person, but by “living as an LGBT person in a homophobic society”.<sup>25</sup> LGBT populations are at a higher risk of disability, poor mental health, smoking, and excessive drinking,<sup>26</sup> experience higher rates of HIV infection, suicide attempts, violence and homelessness, and have less access to preventive health care.<sup>16</sup> The stress of living within a heterocentrist, homophobic society, leading marginalized lives, enduring the stress of hiding one’s sexual orientation, facing verbal, emotional or physical abuse from both family members and the larger society, may lead to engagement in risky behaviours and a wide range of mental health problems.<sup>11,22,25</sup> The risk of depression, generalized anxiety disorder, panic attacks, and the possibility of social isolation is higher within this population.<sup>25</sup>

Studies have shown that better health has been linked to living with a partner, having a higher income and less lifetime victimization, having good physical and mental functioning, higher self-esteem, being a parent, and having a favourable attitude towards one’s own sexuality.<sup>20</sup> However, there is also evidence that older same-sex couples do not gain the same health benefits as heterosexual couples and are at a significantly greater risk for needing some type of long-term care assistance than their heterosexual counterparts.<sup>31</sup> This difference may be due in part to public policies that discriminate against same-sex couples reinforcing the interwoven nature of policy, practice, and health outcomes.

## SOCIAL SUPPORT

Although minority status and stress are often linked to poor health outcomes, this stress is typically mitigated by social support, personality, and personal characteristics like self-esteem and hardiness.<sup>20</sup> For example, older LGBT adults are often supported by their families-of-choice and are no more likely to be depressed than their heterosexual counterparts.<sup>27</sup> Many LGBT persons who deal with stigmatization and victimization on a daily basis develop competence, resilience, strength and coping skills that protect them against poor health outcomes and may even help prepare them for old age.<sup>1,22,32</sup> The coming-out process involves personal growth and self-awareness which may, in turn, increase coping resources.<sup>22</sup>

Support networks are an important source of assistance for people who need help. LGBT persons may have smaller, thinner support networks for a variety of reasons including less likelihood of being partnered and increased probability of living alone and being childless.<sup>17</sup> Fewer family support options and a more precarious economic situation may make formalized, paid care less of an option.<sup>1</sup> Families of choice or chosen support systems may be used more frequently than biological families by older LGBT persons.<sup>5,22,27</sup> However, inherent challenges to support and caregiving by friends must not be overlooked; caregiving friends lack legal power and authority to make medical or end-of-life decisions and may be unable to perform sustained

caregiving tasks over a long period of time.<sup>33</sup>

### LEGAL ISSUES AND END-OF-LIFE PLANNING

Although legal treatment for lesbian and gay persons is improving, LGBT groups continue to experience legal issues and challenges not faced by heterosexuals.<sup>34</sup> Basic family rights and protections are still denied to most LGBT people. As older non-heterosexual adults, they have a long history of being ineligible for most protections provided by the federal elder safety net, although this is changing.<sup>34</sup> Most policies, protections and assistance programs are geared toward heterosexuals.<sup>34</sup> There is a wide discrepancy in local, state, and federal laws.<sup>34</sup> For example, in the United States, Section 3 of the Defense of Marriage Act (DOMA) was struck down by the Supreme Court on June 26, 2013, allowing Social Security benefits to be extended to include partners in legalized unions.<sup>8,35</sup>

Legal uncertainties and lack of recognition of same-sex couples and families of choice increase the need for end-of-life planning to ensure that a person's wishes are honoured and executed and, specifically, to limit the legal power of their families of origin if so desired.<sup>11,19</sup> End-of-life planning documents include advance directives such as living wills and health care powers of attorney; these documents are particularly important for older LGBT adults "because they are the only legal means of safeguarding the authority of a significant other in situations of medical decision making".<sup>11</sup> However, there is no guarantee that these documents will work, and that families of origin will respect same-sex relationships; good communication among affected parties is essential.<sup>11</sup>

### MEETING THE NEEDS OF LGBT PERSONS IN HOSPICE AND PALLIATIVE CARE SETTINGS

Older LGBT adults have identified seven areas of concern including medical/health care, legal, institutional/housing, spiritual, family, mental health, and social issues.<sup>36</sup> Of these, medical/health care, including failing health, financial concerns and rising health care costs, was the primary concern. Spirituality and connection to organized religion is an important aspect of life for many LGBT people, particularly LGBT people of color.<sup>24</sup> Although some religious groups condemn homosexuality<sup>37</sup> which may add stress to a person's life, much depends on how religious doctrines are interpreted and internalized.<sup>11</sup>

With all of the challenges facing the LGBT population, how can hospice and palliative care organizations and services adapt to meet their needs? A welcoming, inclusive, culturally sensitive environment is essential; this would include LGBT friendly forms that acknowledge multiple family types and relationships and appropriate questions about sexual orientation and gender identity, development and display of non-discriminatory policies, brochures and art work that is inclusive, a diverse staff including a designated LGBT liaison, staff training on sensitiv-

ity to LGBT culture, issues and concerns, educational materials on topics pertinent to this population, and LGBT persons' rights to decide who may visit them in accordance with 2011 Medicare and Medicaid policies.<sup>1,4,19,30,38</sup> Ideally, service providers such as hospice and palliative care would be welcoming to all persons and not wait until someone openly identifies as LGBT to activate appropriate services.<sup>38</sup>

Health care providers must understand the cultural context of patients' lives, take detailed, non-judgmental patient histories, and be self-reflective about their own attitudes.<sup>1</sup> Services must avoid heterosexist or homophobic elements<sup>22</sup> and accept gender assignments preferred by transgendered persons.<sup>38</sup> Service providers should be sensitive to stigmatization and its history and be knowledgeable about barriers to care that continue to exist.<sup>39</sup> Lack of knowledge of LGBT populations by service providers should be addressed and rectified; this knowledge should include understanding similarities and differences among LGBT patients, using a life span approach, the role and importance of self-defined family, legal issues, advance directives, employee benefits, and long term care concerns.<sup>25</sup>

Health care can be improved by requiring specific cultural competency training for the treatment of LGBT patients provided by members of the LGBT community; most existing competency training focuses on racial/ethnic minorities<sup>21</sup> without taking into consideration that not all racial/ethnic minority patients will be heterosexual. Since medical personnel receive little to no training regarding LGBT health and cultural competency skills, this deficiency should be addressed.<sup>4</sup> Competency based education should be embedded into the curriculum throughout medical school, not just as an isolated unit.<sup>29</sup> Ongoing competency training for staff is essential.<sup>40</sup> One study found that providing LGBT aging sensitivity training to service providers resulted in positive change at least in the short term.<sup>41</sup> A first step in developing sensitivity and understanding is exploring one's own homophobic or heterosexist biases.<sup>19,25</sup> Hospice and palliative care organizations can learn from the policies and practices of LGBT organizations such as Services and Advocacy for GLBT Elders (SAGE).<sup>42</sup>

The Fenway Institute<sup>16</sup> has suggested some strategies to increase the number of LGBT clients served and the quality of that service. These strategies include the provision of free and low-cost services that meet the needs of LGBT clients, creation of welcoming environments, training for front desk and program staff, provision of appropriate staff training on health insurance issues, and using patient surveys and evaluation forms to elicit feedback. Techniques for creating a welcoming environment include unisex bathrooms, posting 'safe space' or rainbow stickers, and having LGBT magazines or newspapers in waiting areas.<sup>16</sup> To increase enrolment of LGBT patients, recruitment efforts should include going where LGBT people congregate for social support, goods and services, using mobile technology and on-site enrolment techniques, and appropriate advertising.<sup>16</sup> In

addition, these enrolment and recruitment efforts must purposefully and mindfully go beyond solely majority white LGBT people.

## CONCLUSIONS

Lesbian, Gay, Bisexual and Transgender (LGBT) persons constitute a diverse group with a long and varied history. Intersectionality argues that sexual orientation is a single aspect of our complex social identities. LGBT persons represent a minority group struggling to gain political and social acceptance in a heterosexist world in which they encounter marginalization, discrimination and sometimes violence. The chronic stress of heterosexism threatens quality of life and increases the risk of poor health outcomes. LGBT elders who grew up when sexual minorities were stigmatized as pathological, sinful, and immoral may conceal their LGBT identity. Fear of discrimination leads many to avoid seeking care due to concerns about reported rejection. For people needing end-of-life care, stress may be mitigated by social support and resilience. However, LGBT families face unique challenges apart from coping with terminal illness; these include possible prior rejection from family of origin and ambiguous legal relationship-status in many states that jeopardizes basic family rights and protections. The needs of LGBT persons at the end of life may be addressed through a welcoming, inclusive, culturally-sensitive environment, non-discriminatory policies, diverse staff, sensitivity training, pertinent educational materials, and visitation rights in accordance with the 2011 Medicare and Medicaid policies. Sound research is needed to shape changes in policy and training, especially regarding end-of-life issues.

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## CONFLICTS OF INTEREST

We pledge that there is no known conflict of interest in the preparation and publication of this manuscript.

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