

## Seeing Silver in the Spectrum

### LGBT Older Adult Health, Aging, and Gerontological Nursing Research

On June 26, 2015, the United States Supreme Court ruled that the Constitution protects the rights of any U.S. citizen to marry someone of the same sex if they so choose, joining 20 other countries who extend these same rights to all citizens. Many advocates of the civil and human rights of individuals who identify as lesbian, gay, bisexual, and transgender (LGBT) hailed this as a definitive sign of increasing public acceptance in recent years. Others, particularly members of the LGBT community, have called for cautious optimism tempered by the recognition that serious issues affecting the health and well-being of this community endure, including economic and employment insecurity, workplace and housing discrimination, long-term effects of minority-related stress, substance abuse, and poorer health and aging outcomes, including high rates of chronic and comorbid illness, depression, and anxiety.

For older adults who identify as LGBT, the Supreme Court decision on same-sex marriage may be a welcome indicator of a significant sociocultural shift, perhaps one that many LGBT older adults did not imagine happening in their lifetime. But while individuals of many generations are celebrating progress, LGBT older adults have reported feeling a sense of double invisibility in relation to both mainstream heterosexual society and the LGBT community (LGBT Aging Project, 2012; Shankle, Maxwell, Katzman, & Landers, 2003). Members of the same generations who advocated for LGBT visibility and social justice during the Stonewall uprising and the AIDS epidemic have found themselves rendered marginal again due to ageism within the LGBT community (Espinoza, 2013; Woody, 2014) and the risk for discrimination and mistreatment as health status changes, and more formal “outside” support is needed. This situation is especially complex for LGBT older adults of racial, ethnic, and linguistic minority status (Woody, 2014).

Gerontological nursing research is well-positioned to be on the forefront of improving the visibility and outcomes

of LGBT older adults, to raise awareness of the issues affecting their health and aging experiences, and to produce studies with the potential to inform both intervention and education. Unfortunately, nursing as a whole has largely ignored LGBT health, and this is particularly true for the health of LGBT older adults. In a survey of nursing literature published in the top 10 nursing journals (based on 5-year impact factor) between 2005 and 2009, Eliason, Dibble, and DeJoseph (2010) found that only 0.16% of all articles in this sample focused on LGBT health issues for individuals of any age—none of these articles focused on or included LGBT older adults. Applying similar methods, I updated this search to articles published between 2010 and 2014, extending the review to include publications on LGBT older adult health. Since 2009, there has been an overall increase in the number of nursing articles addressing LGBT health, but a significant lack of focus on LGBT older adults persists. Of articles published in the top 10 nursing journals (based on impact factor) during 2010-2014, only one focused on LGBT older adults (<0.01%).

In what follows, a brief review of key issues compromising health and aging outcomes and quality of care for LGBT older adults provides context for understanding the importance of gerontological nursing research stepping it up in this area. Rates of chronic and comorbid illness, systematic barriers to services, experiences of discrimination, lack of provider knowledge and competency, and the failure of nursing research to include LGBT older adults are interrelated factors that collude to enable invisibility and disparities to persist despite other advancements in civil and human rights.

#### SYSTEMATIC DISCRIMINATION AND BARRIERS TO CARE

Estimates on how many older Americans identify as LGBT vary, largely because census data and other population counts historically have not provided options for individuals to self-identify as LGBT. One recent estimate

places the number of individuals older than 65 who are lesbian, gay, or bisexual at 1.5 million, and this number is expected to double by 2030 (Gates, 2011). LGBT older adults are more likely than their heterosexual counterparts to experience poor health and aging outcomes, including chronic illnesses, such as high blood pressure, heart disease, diabetes, cancer, HIV/AIDS, and chronic pain, and are also more likely to have serious mental health issues, including stress, depression, suicidal thoughts, and lack of social support (Addis, Davies, Greene, Macbride-Stewart, & Shepherd, 2009; Fredriksen-Goldsen, Emler, et al., 2013; Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013; Fredriksen-Goldsen, Kim, Muraco, & Mincer, 2009; Institute of Medicine, 2011).

Compounding health and aging disparities, LGBT older adults fear discrimination and mistreatment from service providers across a range of settings, including outpatient care, hospitalization, home health, assisted living, and long-term care. The need to go “back into the closet” to protect oneself while receiving home care services, or when transitioning from community to residential living, is a recurring theme within studies of LGBT older adults’ views on long-term care (Addis et al., 2009; McCabe, Bostwick, Hughes, West, & Boyd, 2010; Van Wagenen, Driskell, & Bradford, 2013).

Fear of discrimination appears to be both widely experienced and well-founded. A national online survey sponsored by six service organizations asked respondents, including LGBT older adults, caregivers, social service providers, and legal representatives, about experiences with assisted living and long-term care ( $N = 769$ ; National Senior Citizens Law Center, 2011). Results indicated that there are considerable barriers to service for this group. Ten percent of respondents reported that LGBT older adults receive inferior care or are denied services because of their orientation; 15% expressed fear seeking health care outside the LGBT community; 21% reported not disclosing their orientation or gender identity to their providers; 89% of respondents believe staff will discriminate against them if their identity is disclosed; and 43% report being mistreated by long-term care staff and administrators. This report also notes that in addition to survey item responses, 328 participants submitted comments in which they reported 853 separate instances of mistreatment (National Senior Citizens Law Center, 2011). Frazer’s (2009) survey of 3,500 LGBT adults older than 50 corroborates risk for mistreatment, with 8.3% of respondents reporting mistreatment by caregivers because of homophobia and 8.9% reporting being blackmailed or exploited by caregivers threatening to disclose their orientation to others.

## **LACK OF KNOWLEDGE AND COMPETENCIES AMONG HEALTH AND AGING SERVICE PROVIDERS**

In U.S. and Canadian medical schools, students receive only 5 hours of education or training related to LGBT patient care, with little or no additional opportunity to learn competency skills during clinical practice (Obedin-Maliver et al., 2011). No comparable studies have quantified the amount of LGBT-focused education received in nursing programs, but nurse scholars have noted a general lack of education and competency training for nurses in this area (Jablonski, Vance, & Beattie, 2013; Lim & Bernstein, 2012; McIntyre & McDonald, 2012; Peate, 2013a,b; Ridgers, 2013).

Research involving LGBT aging services is also scant, but the few studies of knowledge, competency, and attitudes among aging service providers indicate that many providers remain unaware that there are LGBT older adults in their service area. One study (Hughes, Harold, & Boyer, 2011) explored how members of a large Midwestern aging services network were approaching the issue of LGBT aging and LGBT older adult services, including what services specific to this group were available and attitudes of network providers regarding LGBT older adults and training needs. Although the majority of respondents believed that LGBT older adults had different needs related to aging (63%), a sizable minority did not (37%). Although 61% of respondents thought the level and nature of services provided to LGBT older adults by their agencies was appropriate, 32.2% indicated that LGBT-specific services were a low priority for their agency, 29.9% reported that they were somewhat of a priority, and 26.4% reported that they were not a priority. Moreover, the majority of respondents (56.3%) said that their agencies did not engage in any outreach to the LGBT community.

Another study of aging service providers (Knochel, Quam, & Croghan, 2011) found that 65% of respondents were not aware of the existence of lesbian and gay older adult-specific aging services throughout the United States; 81% of respondents reported that staff did not receive training specific to this population, and although 61% agreed that it was important to address the needs of older lesbian and gay adults, 10% were unwilling to consider competency training focused on the topic.

## **LACK OF GERIATRIC AND GERONTOLOGICAL NURSING RESEARCH WITH LGBT OLDER ADULTS**

Nursing science has been relatively silent on the topic of LGBT older adult health and aging, even when research concerns diagnoses, conditions, situations, and experiences that affect the health and well-being of individuals in the

LGBT community as much—or even more so—than other social groups. A systematic review of the nursing literature published between 2010 and 2014 yielded 71 articles with any mention of LGBT terms published in the top 10 nursing journals and in two journals focused on gerontological and geriatric nursing. Of these, 11 had a substantive focus on LGBT health; four included LGBT older adults and two had a substantive focus on LGBT older adult health or aging. Only one of these articles appeared in the top 10 nursing journals, representing less than 0.01% of articles published in top-impact nursing journals. Expanding the review to nursing journals regardless of impact ranking identified 15 additional articles published in 2010 through March 2015 that explicitly focused on LGBT older adult health or aging and/or included LGBT older participants. Two thirds of these publications ( $n = 11$ ) were authored by researchers and scholars outside the United States.

### FROM SILENCE TO SCIENCE: MOVING TOWARD INCLUSIVITY AND COMPETENCY

When our scientific and clinical discourse is driven by the directive of evidence-based practice, the lack of nursing research either explicitly including or focusing on LGBT older adults is telling. Nursing research as a whole, and gerontological nursing research in particular, should take specific steps to address this gap in our knowledge and practice.

The state of the science on LGBT older adult health and aging is emerging and thus is largely descriptive at present. Because of this, higher impact journals may need to adjust their review criteria to promote the visibility and inclusivity of LGBT-centered work for a broader audience of nurses with the power to implement findings. Moreover, nurse researchers conducting research in areas that clearly affect LGBT older adults, including chronic illness, dementia, cancer, and caregiving, should be required to demonstrate competence regarding inclusivity in their study designs. Thoughtful consideration must be given to how conventional design of surveys, questionnaires, and self-report measures may perpetuate the systematic exclusion or full involvement of LGBT participants, eliminating the knowledge and insight to be gained from their experiences and, in some cases, erasing this group altogether. The day when federal funding agencies include LGBT participants as part of their minority target enrollment requirements may not be far off, and systematic plans for inclusion of LGBT participants—or sound rationale for purposeful exclusion—will be required.

Other aspects of the research process also require attention, including the theoretical models used to organize in-

quiry and education. Nurse scientists and educators need question-dominant models and frameworks for the heteronormative assumptions that exclude and marginalize older adults whose histories and experiences are not included in their development. Any sacrifice in generalizability would be offset by gains in inclusivity and, therefore, validity and explanatory power. Theorizing health and aging processes from the standpoint of intersectionality or life course perspectives offers promising, empirically sound alternatives. Such a stance would be useful not only for LGBT-focused gerontological research, but for any research including groups whose collective and individual histories are best understood in terms of an intersection between personal identity, social categorization, and systematic discrimination and marginalization.

The silence of gerontological nursing research regarding LGBT older adult health compounds the silence of nursing in general and compromises the opportunity of nursing science to lead in this critical area of need. As nurses, we cannot practice what we do not know, just as we cannot question or counteract that of which we remain unaware. Lack of systematic, contextual, and practical knowledge regarding the collective and individual histories and experiences of LGBT older adults hampers our ability to be fully competent in research and practice.

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