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Cognitive Impairment, Alzheimer's Disease, and Other Dementias in the Lives of Lesbian, Gay, Bisexual and Transgender (LGBT) Older Adults and Their Caregivers: Needs and Competencies

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Abstract

Cognitive impairment, Alzheimer's disease, and other dementias are important health concerns for older adults. As a marginalized and growing segment of the older adult population, lesbian, gay, bisexual, and transgender (LGBT) older adults face distinct risk factors related to cognitive impairment and dementias, including social isolation, discrimination, barriers to health care access, limited availability of and support for caregivers, and higher rates of certain chronic illnesses. We examine cognitive impairment and dementias among LGBT older adults, describe their unique risk factors, and outline key competencies for health care and human service providers to

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ensure culturally relevant care for LGBT older adults experiencing cognitive impairment, Alzheimer's disease, or other dementias, as well as their caregivers, families, and communities. Implications include developing an awareness of the context of LGBT older adults' lives and relationships, the importance of early detection and support, and the development of policies and practices that promote community-level advocacy and education.

Keywords
Alzheimer's, dementia, cultural competency, services

Cognitive impairment, Alzheimer's disease, and other dementias are important health concerns for older adults. Alzheimer's disease, the most common form of dementia, affects an estimated 5.4 million Americans, including 5.2 million who are 65 years old or older (Alzheimer's Association, 2016b). Cognitive impairment is even more prevalent than Alzheimer's and other dementias. In the Aging, Demographics, and Memory Study, an estimated 5.4 million U.S. adults aged 71 and older had cognitive impairment without a diagnosis of dementia, or approximately 22% of this population (Plassman et al., 2008) and 14% were living with some form of dementia (Plassman et al., 2007). Approximately 3.4 million new cases of dementia and an additional 4.8 million cases of cognitive impairment occur every 6 years in the U.S. population aged 72 and older (Plassman et al., 2011). These conditions produce a high burden of care costs and responsibilities. In 2016, an estimated $236 billion will be spent on care and treatment of individuals 65 years of age and older with Alzheimer's disease and other dementias, making it the most expensive disease in America (Alzheimer's Association, 2016b) and accounting for 20% of all Medicare expenditures (Alzheimer's Association, 2016a). In addition, approximately 18 billion hours of unpaid care, estimated to be valued at $221.3 billion, was provided to this population (Alzheimer's Association, 2016b). At the individual level, health care and long-term services, including out-of-pocket expenses, for those living with Alzheimer's and other dementias is nearly $30,000 per year for those living at home and more than $77,000 per year for those in a residential facility. Furthermore, the value of unpaid caregiving is approximately $40,000 per year for each individual in this population (Alzheimer's Association, 2016b), which does not include an additional average of $13,188 in wages lost in time spent caregiving (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). Yet not all older adults have access to high-quality paid or unpaid care and support. One population of particular concern is lesbian, gay, bisexual, and transgender (LGBT) older adults.

The LGBT older adult population is rapidly growing and health disparate: approximately 2.7 million U.S. adults aged 50 and older currently self-identify as LGBT, including 1.1 million aged 65 and older; these figures are projected to double by the year 2060 (Fredriksen-Goldsen, 2016; Fredriksen-Goldsen & Kim, 2017). Given U.S. Census projections of the growing older adult population, we estimate that by 2060, those that self-identify as LGBT and/or engage in same-sex behavior or have had romantic relationships with members of the same sex will number nearly 20 million. Aging With Pride: National Health, Aging, Sexuality and Gender Study (hereafter "Aging With Pride"), funded by the National Institutes of Health and the National Institute on Aging, is the first longitudinal national study to investigate LGBT aging, health, and well-being, including cognitive impairment and decline as well as diagnoses of Alzheimer's disease and other dementias among a demographically diverse sample of 2,450 LGBT adults aged 50 to 100 years. According to recent estimates from the CDC (2011), between 9% to 15% of adults age 50 and older are living with cognitive impairment, which would account for 240,000 to 400,000 LGBT older adults of the same age; this includes approximately 121,000 LGBT adults 65 and older living with Alzheimer's disease. The estimated annual costs associated with care of LGBT older adults living with Alzheimer's disease and other dementias, as a health disparate population, is in excess of $17 billion.

The Patient Protection and Affordable Care Act (ACA) aims to reduce health disparities by mandating culturally competent practice in health care settings with "special" populations, generally minority populations, including LGBT older adults (Health Resources and Services Administration, 2012). Yet, even though many educational accreditation bodies address the need for culturally competent practice in health and human service settings, practitioners across disciplines often lack adequate knowledge and skills for culturally relevant and effective practice with LGBT populations within diverse settings. Aging With Pride provides a unique opportunity to explore the needs of LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias and to develop competencies for providers to better address their needs.

Methodology

This article builds on an earlier published article that outlined 10 core competencies for professional practice in the health and human services with LGBT older adults and their families (Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emlet, & Hooyman, 2014). The original core competencies for practice with LGBT older adults and their families were developed through a systematic analysis of existing research findings and the extant literature on LGBT aging, and existing competencies for culturally relevant practice with older adults, including core competencies required by the Council on Social Work Education's (CSWE; 2008) Educational Policy and Accreditation Standards (EPAS) and the 2009 Geriatric Social Work Competency Scale II with Life-Long Leadership Skills (GSW II; see https://www.pogoe.org/sites/default/files/GeriatricSocialWorkCompetencyScaleII%26LifelongLeadershipSkills.pdf)

These developed competencies filled an important gap in training and education related to LGBT aging, laying a framework for the development of more specialized guidelines designed to target specific content areas. To develop key competencies for specialized practice with LGBT older adults living with cognitive impairment and Alzheimer's disease and other dementias, as well as their families and caregivers, we conducted systematic reviews of the original competencies developed as they applied to cognitive impairment, Alzheimer's disease, and other dementias. Next, we analyzed research findings from Aging With Pride and existing literature on LGBT aging as well as literature focusing on culturally competent practice in Alzheimer's disease and dementia care. The development and articulation of the key competencies presented here are based on the findings across these varied sources as they were relevant to build knowledge, skills, and attitudes necessary for effective practice with LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias, and their families and caregivers.

In this article, we define cognitive impairment and dementia and provide an overview of factors that place LGBT older adults at elevated risk. We outline key competencies for health care and human service providers who work with LGBT older adults living with cognitive impairment or dementia, as well as their caregivers, families, and communities. We also outline next steps for services, public policies, and research to better address the needs of diverse cognitively impaired older adults.

Cognitive Impairment, Alzheimer's, and Other Dementias in LGBT Communities

Cognitive impairment, "when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life" (Centers for Disease Control and Prevention [CDC], 2011, p. 1), is a risk factor for developing dementia later in life (Plassman et al., 2011). *Dementia* is a severe type of cognitive impairment “characterized by a decline in memory, language, problem-solving and other cognitive skills that affects a person’s ability to perform everyday activities” (Alzheimer’s Association, 2016b, p. 5). Dementia can be caused by a range of conditions that damage nerve cells in the brain, most commonly *Alzheimer’s disease* but also including vascular dementia, dementia with Lewy bodies, frontotemporal lobar degeneration, Parkinson’s dementia, and Creutzfeldt-Jakob disease. A small percentage of dementia cases (1% or less) are caused by specific genetic mutations and carrying the APOE-e4 gene, which can increase one’s chances of developing dementia. Modifiable risk factors for developing dementia include depression, cardiovascular disease (CVD), smoking, obesity, lower education, and limited social or cognitive engagement (Alzheimer’s Association, 2016b; Caraci, Copani, Nicoletti, & Drago, 2010).

Some of these risk factors are known to be more prevalent in LGBT older adults and their communities, putting them at higher risk of developing cognitive impairment, Alzheimer’s disease, or other dementias. In Aging With Pride, we assessed LGBT older adults’ cognitive functioning and asked if they had been diagnosed with Alzheimer’s disease or another dementia. Cognitive functioning was measured with the World Health Organization Disability Assessment Schedule (WHO-DAS) II cognition domain, on which participants rate their level of cognitive difficulty during the past 30 days in six areas (concentration, memory, problem solving, learning, comprehension, and communication) (Üstün, Kostanjsek, Chatterji, & Rehm, 2010). We found that 10% reported *severe or extreme* cognitive difficulties in at least one area, 38% reported *moderate* cognitive difficulties in at least one area, and 77% reported *mild* cognitive difficulties in at least one area. Cognitive difficulties were elevated among LGBT older adults who were African American, Hispanic, HIV-positive, male, and those who identified their sexual orientation and/or gender as “other.” Despite some participants reporting high levels of cognitive difficulty, just under 1% of those aged 80 and older reported a diagnosis of Alzheimer’s disease or another dementia, far less than expected considering that about one third of Americans aged 85 and older are living with Alzheimer’s disease alone (Alzheimer’s Association, 2016b). The low rate of diagnosis we observed may, in part, reflect that the severely impaired are unlikely to complete a self-administered questionnaire, that physicians often do not report a diagnosis of Alzheimer’s disease or other dementias directly to patients (Alzheimer’s Association, 2016b), or that dementia is less likely to be detected in LGBT older adults. These findings highlight the need to identify predictors of cognitive problems specific to LGBT adults.

Unique Risk Factors for LGBT Older Adults

Today's LGBT older adults grew up in a time when sexual and gender minority statuses were severely pathologized. Compounding effects of multiple sources of stigma (i.e., sexual and gender minority status, cognitive difficulties, old age) likely create barriers to accessing routine health care, causing cognitive impairment to go unnoticed and untreated. Additionally, more than one in 10 LGBT older adults (13%) in Aging With Pride, including 40% of transgender participants, report they have been denied health care or provided with inferior health care due to the perception of their sexual or gender identities (Fredriksen-Goldsen, Cook-Daniels, et al., 2014; Fredriksen-Goldsen et al., 2011). In our study, 15% of LGBT older adults reported a fear of accessing health care outside of the LGBT community and 8% a fear of accessing health care inside the LGBT community, presentingsignificant barriers to health care access.

Discrimination and identity concealment also put LGBT older adults at elevated risk for social isolation and loneliness (Kim & Fredriksen-Goldsen, 2014; Kuyper & Fokkema, 2010), which have been linked to poorer physical and mental health (Cornwell & Waite, 2009), increased mortality (Steptoe, Shankar, Demakakos, & Wardle, 2013), and increased risk for developing cognitive impairment or dementia (Cacioppo & Hawkley, 2009). Social isolation may hasten cognitive decline, create deficits in safety, and limit access to services (Alzheimer's Association, 2016b; Webber, Fox, & Burnette, 1994). Many older adults rely on immediate family members for care and support, but LGBT older adults are less likely than heterosexuals to have children or be married and are more likely to live alone (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013). They are also more likely to be acting as caregivers for friends and other extended kin. Among LGBT older adults in Aging With Pride, more than one quarter (27%) were providing caregiving assistance (Fredriksen-Goldsen et al., 2011). Caregivers who are not legal or biological family members often have limited legal power to be involved in the issues of consent and decision-making that arise in the context of worsening cognitive decline if they are not designated as a health care proxy (Fredriksen-Goldsen et al., 2011). For instance, their input may be excluded when determining where their loved one will reside or what health care treatments they receive.

In terms of health-related risks, gay and bisexual men are more likely than their heterosexual peers to have HIV/AIDS, which can complicate other health conditions, damage the brain, and contribute to cognitive decline. HIV-associated dementia is experienced by 7% to 27% of individuals with late stage HIV and milder cognitive impairment by 30% to 40% (Huang, 2015). LGBT older adults are also more likely to smoke than heterosexuals of similar age, lesbian and bisexual women have higher rates of CVD and obesity, and one third of LGBT older adults report depression (Fredriksen-Goldsen, Kim, et al., 2013), all risk factors for cognitive decline and dementia.

Despite the unique risks experienced by LGBT older adults related to cognitive impairment and dementia, this population exhibits strengths in their ability to maintain a positive sense of identity, adapt to adversity, and build community (Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emlet, 2015). During the height of the HIV/AIDS pandemic, which severely threatened this community and took the lives of many gay and bisexual men and transgender older adults, in particular, LGBT communities joined together and formed supportive networks to provide care to one another, demonstrating a collective resilience despite a diversity of identities and experiences. Thus, unique configurations of both risk and resilience are present in this community, both of which inform the competencies presented here.

Key Competencies and Priority Needs

Given these risk factors (i.e., historical context, unique family structures, barriers to care, caregiving burden, and health factors), below we outline key competencies for working with LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias, and their families and caregivers.

Competency 1: Attitudes

> Critically analyze personal and professional attitudes toward LGBT older adults (including their sexual orientation, gender identity, gender expression, and age), as well as cognitive impairment and Alzheimer's disease and other dementias. Understand how such attitudes influence the care of LGBT older adults, families, and caregivers managing cognitive decline.

Societal and personal biases, including homophobia, heterosexism, transphobia, and ageism, impact the day-to-day lives of LGBT adults living with cognitive impairment, Alzheimer's disease, and other dementias. Health and human service providers may hold such biases, which, if unaddressed, can lead to overt discrimination, unconscious prejudice (Foglia & Fredriksen-Goldsen, 2014), and micro-aggressions, experiences that serve to devalue or ignore the experiences of people who hold marginalized identities (Nordmarken, 2014). Such manifestations of bias are harmful to the provision of sensitive care. Additionally, cognitive impairment may both directly result in stigma and magnify some of the features associated with aging that are devalued (e.g., forgetfulness, slowed cognitive processing). Thus, providers' personal biases may intersect, be intensified, and serve to further compound the social marginalization of LGBT people (Fredriksen-Goldsen, Simoni, et al., 2014).

Providers must make a concerted effort not to conflate symptoms of cognitive impairment with attitudes about the client's status, value, or deservingness of quality care. For example, dementia can lower impulse control and clients may say or do things a provider experiences as rude or unpleasant. Providers must work to understand such instances for what they are—symptoms of the disease—and not as evidence to substantiate other personal biases. Lowered inhibitions associated with cognitive decline may also place LGBT older adults with dementia at risk for disclosing their sexual or gender identity in unsafe environments, thereby incurring added vulnerability to potential bias from providers and, in long-term care settings, other residents. This can lead to or exacerbate ethical dilemmas already present in dementia care concerning the privacy and safety of patients (McGovern, 2014).

Tools are needed to alter attitudes toward sexual and gender minorities and dementia. There is emerging evidence that direct interaction with people living with dementia and engagement in shared and mutual activities can reduce stigma and improve attitudes of care providers (George, Stuckey, & Whitehead, 2013). It is also important for providers to have opportunities for direct contact with LGBT older adults living with cognitive decline so that assumptions and stereotypes directly related to sexual orientation and gender identity and expression are surfaced. Overall, providers must regularly assess their own attitudes and beliefs and actively build skills to combat the impact of personal biases on effective service delivery, as well as to handle the ethical dilemmas that arise in providing care to LGBT older adults living with cognitive decline and their families and caregivers.

Competency 2: Historical, Social, and Cultural Context

> Understand and articulate the ways in which historical, social, and cultural context negatively impact LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias, especially how past experiences may alter needs and behaviors in relation to cognitive impairment and help-seeking behaviors.

LGBT older adults report high lifetime rates of discrimination and other traumas and stressors related to their perceived sexual and/or gender identities

(Fredriksen-Goldsen, Cook-Daniels, et al., 2014; Fredriksen-Goldsen, Emlet, et al., 2013). These lifetime histories may give rise to unique needs when cognitive impairment is present. For example, some people living with cognitive impairment find that memories of traumatic experiences are unclear but emotional reactions and triggers are intact. Trauma experiences can accentuate what Volicer (2012) terms "rejection of care," when patients resist care from providers or show aggression toward care providers who attempt to help them. Extra emotional support may need to be provided to increase the quality of life of patients and reduce negative interactions with providers, particularly among those most severely impaired.

Historical circumstances may also impact LGBT older adults' decisions about identity disclosure (including to health care providers) and utilization of services. Many LGBT older adults report that they want to age in LGBT-friendly retirement communities (Stein, Beckerman, & Sherman, 2010; Sullivan, 2014) and that they prefer LGBT-friendly services (Gardner, de Vries, & Mockus, 2014), but few currently exist. Thus, many LGBT older adults are aging and accessing services in settings in which they may be uncomfortable or have faced discrimination in the past. Providers need to develop skills so they can signal safety to LGBT older adults. Direct care (particularly bodily care) should be approached with sensitivity and tailored communication styles, such as talking in soothing but not patronizing tones, explaining and receiving consent for each action of the care provider before the action occurs, and encouraging clients to complete tasks independently when they are able.

Although there are few tested interventions that focus on improving cultural competence of providers working specifically with LGBT older adults and their families and caregivers, increased awareness of historical impacts of societal marginalization and discrimination has potential to cultivate provider empathy and understanding (Leyva, Breshears, & Ringstad, 2014; Rogers, Rebbe, Gardella, Worlein, & Chamberlin, 2013). When historical impacts of marginalization have been discussed in trainings through the personal narratives of LGBT older adult panelists, training participants stated that having LGBT older adults present promoted their understanding by "putting a face on the issues" (Rogers et al., 2013, p. 590). These kinds of educational experiences are useful to translate narrated experiences into competent practice.

Competency 3: Intersecting Identities and Subgroups

> Distinguish similarities and differences within the subgroups of LGBT older adults, as well as among individuals' intersecting identities (such as age, gender, race, ethnicity, ability status, and socio-economic status), to

> develop tailored and responsive care strategies for cognitive impairment, Alzheimer's disease, and other dementias.

Within the population of LGBT older adults, there are distinct subgroups defined by sexual and gender identity groups as well as other background and demographic characteristics (e.g., biological sex, gender, age, race and ethnicity, disability status, socio-economic status, and others). Diversity of intersecting identities and experiences, including cognitive impairment, leads to differing configurations of risk and resilience, associated with different treatment and support needs. For example, if cognitive impairment necessitates intimate personal care that involves having one's body exposed, this care may be experienced as extremely intrusive for LGBT older adults. The extent of discomfort this causes will differ depending on a number of factors, such as identity management, gender transition status, history of discrimination and victimization, and prior experiences in care and other service settings. Thus, providers should both be familiar with literature on distinct subgroups and consult with specialists who have expertise in working within specific subgroups. The information gleaned from such sources should be balanced with efforts to know and understand each individual patient.

Subgroups might also be identified by other marginalized identities, such as race and ethnicity. As noted above, we find that African American and Hispanic LGBT older adults report significantly higher rates of cognitive difficulties compared with non-Hispanic Whites, which is consistent with racial disparities in the general population. Research suggests that there may be a "double disadvantage" of living with dementia as a racial or ethnic minority, which may create greater disparities in care (Connolly, Sampson, & Purandare, 2012). Subgroups might also be identified in other ways, such as differences in health behaviors. For example, current smokers are at higher risk of all-cause dementia, Alzheimer's, and Vascular dementia compared with those who have never smoked (Zhong, Wang, Zhang, Guo, & Zhao, 2015), and some studies find that LGBT people are at higher risk of smoking than heterosexuals of similar ages (Balsam, Beadnell, & Riggs, 2012). These risk factors should also be considered in identifying at-risk subgroups.

Competency 4: Application of Theoretical and Practice Perspectives

> Understand, apply, and advocate a practice perspective supporting person-centered care, and actively stay abreast of and utilize relevant theoretical,

intervention, and research literature to engage in up-to-date culturally competent practice with LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias.

In dementia care and cognitive supports, a broad knowledge of different conceptual perspectives can help providers creatively address and define the needs, issues, and strengths of clients. Although practice and theory literature relevant to cognitive impairment are often focused on diagnoses of Alzheimer's disease and other dementias at severe levels, it is important to recognize that these conditions are progressive, developing over time. Using a lifespan perspective can help providers offer assistance that contextualizes a person's cognitive status so that it is responsive to current symptoms while also planning for future needs.

A well-defined practice perspective can facilitate providers' understanding of the unique experiences of marginalized older adults' lives. One important recent development is a focus on person-centered care, which emphasizes the person rather than the illness as the unit of care. Dementia has been defined as a "master status," through which all other information about a person is viewed or filtered, leading staff to identify the disease rather than the person as the source of behaviors (Doyle & Rubinstein, 2013). Although it is useful for providers to recognize when behaviors truly are affected by the disease, they must also balance this view with recognition of other dimensions of the person that influence behavior and needs. Using terms such as "person living with dementia" as opposed to "dementia patient" can serve to centralize the person instead of their patient status or the disease (Young, Manthorp, Howells, & Tullo, 2011). Sexual and gender minority statuses are also often treated as "master statuses." There may be a tendency by providers to over-emphasize, for example, the centrality of a transgender individual's gender identity and expression to dementia care. This may produce probing and invasive questions regarding gender transitions even when not relevant to the presenting condition.

Recent work on the socially constructed self is also relevant to dementia care. Cognitive decline may shift one's experience of self and how one presents to others. For example, sexual minority older adults have often passed as heterosexual at some point in their lives, using widely varying strategies to identify or conceal their identities based on the context (Rosenfeld, 2009). Declining cognitive ability further complicates the ongoing challenge of managing disclosure of sexual and gender identities. Providers should be sensitive to ensuring privacy and confidentiality of information including disclosure of a sexual or gender identity.

Competency 5: Assessment and Interviewing

> Use a comprehensive biopsychosocial assessment with cognitive screening questions to promote early detection. Use empathy and sensitivity during assessment and interviews with LGBT older adults, ensuring the use of appropriate language while taking into account the level of cognitive functioning.

Healthy People 2020 identifies improving diagnosis and early detection of Alzheimer's disease and other dementias as a key health initiative (U.S. Department of Health and Human Services & Office of Disease Prevention and Health Promotion, 2012). Only 45% of individuals living with Alzheimer's disease and 27% living with other forms of dementia report being told of their diagnosis, compared with 90% of individuals living with cancer. It is in the interest of patients' autonomy and involvement in care decisions to be diagnosed early in their disease process and given all available information. Those diagnosed in early stages have more time to plan for the future, including financial planning, creating advance directives specific to their cognitive needs, and ensuring their families and caregivers benefit from early access to supportive services (Alzheimer's Association, 2016b). It is imperative that at-risk LGBT older adults be assessed early for cognitive impairment, Alzheimer's disease, and other dementias and that physicians inform them directly of a diagnosis. Patients from other marginalized populations (e.g., racial and ethnic minority patients) often do not seek physician consultation early in the disease process because they are unsure about the severity of the problem, feel changes are normal due to aging, feel challenged discussing forgetfulness with their loved ones, or are uncomfortable confronting the prospect of dementia (Clark et al., 2005; Griffin-Pierce et al., 2008). Similar factors are likely at play for LGBT older adults and their families and caregivers. Such barriers to detection illustrate the importance of increased education targeted to LGBT communities and the role of service providers in ensuring that cognitive examinations are included in biopsychosocial assessments.

Certain aspects of communication are particularly important for providing LGBT older adults with a safe, welcoming, and positive interview or assessment experience. There is a broad array of terms used to represent differing sexualities, gender identities, and expressions, and there are differences between individuals' preferred terminologies (Fredriksen-Goldsen, Hoy-Ellis, et al., 2014). Providers may inadvertently harm the provider–patient relationship if they unknowingly use an offensive term or persist in using a term that is not preferred; thus, it is important to listen to the language used by the LGBT older adult, their family, and their caregivers, and be willing to explicitly ask for preferred terminology if necessary. Appropriate language may also differ based on the type and severity of the cognitive impairment. To facilitate communication, the Alzheimer's Association suggests being patient, offering comfort and reassurance, not correcting or arguing, and focusing on the feelings behind the words rather than facts. Patience with individuals who are searching for words can ensure that they have the time needed to articulate issues or problems related to their sexual and gender identity.

Competency 6: Personal Relationships

> Be aware of, and able to address, the needs and changes in LGBT older adults' personal relationships with partners, caregivers, and others. Facilitate communication and be sensitive to the intimate and sexual needs of LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias.

As dementia progresses, individuals might forget or fail to recognize important historical or personal events and even the people in their lives (Alzheimer's Association, 2016b). As a result, older adults living with dementia often experience changes in their relationships with partners, family, friends, and others. Intimate relationships may become less intimate, more distant, or less sexual over time as partners take on the role of caregivers and as those living with dementia become less able to carry out their own personal care and hygiene activities. Friendships can also change in their nature, frequency of contact, and length of visits. These changes occur for anyone living with dementia, but may be especially central for LGBT older adults, who are more likely to rely on partners and friends for care. In addition to fears about losing a sense of self, LGBT individuals may have an added concern about being distanced from their communities as cognitive decline progresses, rendering them "doubly invisible" (McGovern, 2014) due to their social identities and their disease. Providers should be prepared to counsel patients, family members, and caregivers through such changes in their relationships and help them understand how to maintain the social support they need.

Providers must also be aware of and sensitive to the sexual needs of older LGBT individuals living with dementia, and comfortable addressing these needs with the older adult and their partners and caregivers. Despite debates about ethical implications of sexual behavior among people living with dementia, it is increasingly recognized that individuals with dementia can and do form meaningful relationships (Everett, 2007), including positive intimate and sexual contact (Archibald, 2003). LGBT older adults who require residential care may have limited privacy in which to engage in sexual activities and providers may feel uncomfortable discussing sexuality with them. Yet it is vital that sexual needs and safety be discussed and supported for older adults' well-being. Staff training and education need to include information about sexuality in later life, providing a safe environment for sexual expression, exploring how sexual needs can be met or redirected when necessary, and open discussion of ethical concerns (Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2010). Providers also often need training on how to effectively discuss issues of sexuality with family and friends, with the goal of effectively supporting the care of the client.

Competency 7: Supporting Caregivers

> Assist caregivers in providing care and accessing support services to address strain, depression, or other challenges that may arise in the course of the caregiving role.

Compared with other caregivers, dementia caregivers provide more help with daily activities and experience more disruption of social activities, interrupted sleep, and depressed and hopeless feelings (Moon & Dilworth-Anderson, 2015). They are also more likely to provide help for long durations of time and with a wide range of daily tasks including direct personal care (Alzheimer's Association, 2016b). Approximately 60% of caregivers rate their emotional stress as high or very high, 38% rate their physical stress as high or very high, and 40% suffer from depression (Alzheimer's Association, 2016b). The demands of caregiving may be heightened among LGBT caregivers. Between 20% and 27% of LGBT midlife and older adults provide care to someone they know (Croghan, Moone, & Olson, 2014; Fredriksen-Goldsen et al., 2011; MetLife Mature Market Institute, 2006). LGBT caregivers, compared with non-caregivers, experience significantly higher levels of depression, disability, victimization, discrimination, and stress, placing them at heightened risk of poor health and quality of life (Fredriksen-Goldsen et al., 2011). Caregiving trends in LGBT communities show some similarities and some differences compared with those of the general population. About two thirds of dementia caregivers in the U.S. general population are women, but in LGBT communities both men and women have a high likelihood of caregiving. In the general population, African American and Hispanic caregivers provide more hours of caregiving and experience higher levels of burden compared with non-Hispanic White caregivers (Alzheimer's Association, 2016b). Among LGBT older adults, Hispanic and Native American individuals were more likely to be providing care than other racial groups (Fredriksen-Goldsen et al., 2011).

Despite high need for caregiver support, only one third of Area Agencies on Aging (AAAs) have trained staff on the specific needs and issues of LGBT older adults (Knochel, Croghan, Moone, & Quam, 2012). Since most caregiving services and supports have been developed to address the needs of caregivers related by blood or marriage, few are tailored for individuals providing care to a friend or unmarried partner and such caregivers often lack the legal standing necessary for decision-making (which will be further discussed below). Thus, providers must be prepared to educate caregivers about issues associated with providing care, assess the support needs of individual caregivers, and connect them with the most appropriate resources available.

Competency 8: Services, Programs, and Agencies

> Understand and articulate the ways in which services, programs, and agencies create welcoming, affirming, and supportive environments for LGBT older adults living with dementia.

Due to past discrimination and ongoing marginalization of LGBT older adults, there remains a lack of consistent and affirming communication between health service agencies and LGBT communities. This barrier contributes to the failure of LGBT voices to be heard and of health education efforts to reach these communities. Without building trust between service providers and communities, LGBT patients and caregivers will have their needs neither recognized nor met. In a recent survey of AAAs, only 13% of agencies reported that they provide targeted outreach to the LGB community, and less than 8% had specific services for these populations. Although three quarters of respondents felt that LGB older adults would be welcomed at their agencies, about 12% did not indicate a welcoming environment. More than 80% were willing to offer staff trainings on LGB aging, but only 34% had already offered such trainings (Knochel et al., 2012). Even fewer agencies offered trainings specific to transgender clients. Because AAAs may be unaware of LGBT older adults in their client base, it is difficult to ascertain how effectively they are actually providing services to this population (Knochel et al., 2012).

Targeted outreach is needed for LGBT older adults with cognitive impairment and their caregivers due to their high risk for social isolation and barriers to care. At the agency or facility level, McGovern (2014) suggests promoting greater inclusivity through using welcoming language in promotional materials or creating specialized materials for LGBT patients with cognitive impairment and their caregivers. Recently, the Alzheimer's Association has reached out to LGBT older adults via advertising, educational materials, and caregiver support resources such as the LGBT Caregiver Concerns pamphlet (2015). Providing bridging services across LGBT organizations and dementia/caregiving supports may also help hard-to-reach populations receive accessible and coordinated care across agencies. Knochel and colleagues (2012) suggest that AAAs and other "mainstream" senior services build partnerships with agencies aimed at reaching LGBT older adults. Hiring staff who identify as LGBT and have experience working with individuals living with dementia in their personal or professional lives may also signal to clients a safe environment and provide opportunities for agencies to strengthen community partnerships and identify unmet needs. Finally, the voices of LGBT older adults should be included in evaluating the effectiveness of new and existing outreach strategies and services (Knochel et al., 2012). LGBT older adults within and outside the agency are well positioned to provide expertise on their experiences and help shape new advocacy and outreach initiatives.

Competency 9: Policies and Laws

> Understand and articulate the ways that local, state, and federal policies and laws address the needs of LGBT older adults, family members, and caregivers living with dementia, as well as address capacity, decision-making, and consent, to advocate on their behalf.

Beyond the agency or facility, providers need to understand the continually shifting legal issues at local, state, and federal levels that impact LGBT clients living with cognitive impairment or dementia. On June 26, 2015, the United States Supreme Court upheld same-sex marriage as a fundamental right in *Obergefell v. Hodges*. Marriage plays a critical role in determining eligibility for Social Security benefits, including survivor benefits, and the processing procedures and applications for spousal and survivor's benefits from same-sex couples are being updated (Lobosco, 2015; Social Security Administration, 2015). Legal marital status also affects eligibility for programs such as Supplemental Security Income (SSI; Social Security Administration, 2015) and Medicaid (Dickson, 2015), federal programs that provide stipends and health care to low-income populations. Among the participants in Aging With Pride, almost one third were living at or below 200% of the federal poverty level, including almost 50% of transgender older adults (Fredriksen-Goldsen, Cook-Daniels, et al., 2014; Fredriksen-Goldsen, Emlet, et al., 2013) indicating a high level of economic vulnerability, which may limit access to health care and intensify the financial hardships associated with spousal bereavement.

Beyond creating access to economic resources, marriage also impacts legal authority to make decisions for a partner living with cognitive impairment or dementia. If unmarried individuals do not have legal documentation in place, such as a durable power of attorney for health care, they may be unable to make decisions for extended kin and loved ones. While these protections are important for any LGBT person, cognitive impairment or dementia is an important reason to discuss preferences early and while clients have the capacity to do so. Clients should also be encouraged to complete documentation specific to hypothetical circumstances involving dementia and end-of-life care; for example, a living will is important to guide decisions of health care proxies (Lambda Legal, 2015). Compassion and Choices, a national organization, has created a registry of advance directives by state and a “Dementia Provision” that can be used to augment other advance directives. Caregivers should be aware of the wishes of their loved one across a wide variety of circumstances, for example, consenting to continued sexual contact or determining ideal living situations in advance of specific need. Providers often need training to be well versed in initiating such conversations with LGBT clients who may or may not have anyone in their life to designate as a decision maker.

To date there remain insufficient federal protections banning discrimination based on sexual orientation and gender identity and expression in a variety of areas, including health care and public accommodations. However, some important changes have been made. State-level public accommodation non-discrimination laws, which generally include medical and long-term care facilities, exist in 18 states plus the District of Columbia and prohibit discrimination based on sexual orientation and gender identity, with three additional states including sexual orientation only (Movement Advancement Project, 2016). The Affordable Care Act also prohibits discrimination based on gender identity or sex stereotyping in hospitals and other health programs or facilities that receive federal financial assistance (National Women’s Law Center, 2016). The federal Nursing Home Reform Act protects residents’ rights to privacy, visitors, and self-determination, among others, although explicit protections for sexual and gender minorities are needed (National Center for Transgender Equality, 2016). Only 11 states plus the District of Columbia have laws prohibiting health insurance discrimination based on sexual orientation and gender identity, and in 39 states there is either no explicit Medicaid policy related to coverage of health care related to gender transition or the state Medicaid policy explicitly excludes such care (Movement Advancement Project, 2016). Thus, the potential for discrimination in health services and facilities remains. Given these recent changes in social policy and the ongoing threat of discrimination, it is crucial that practitioners actively stay abreast of policy changes and be able to explain the rights of and the resources and necessary legal documentation for LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias. They must also address LGBT-related discrimination within their institutions and the surrounding societal context to support the needs of their LGBT clients and their families.

Competency 10: Advocacy and Capacity Building

> Enhance the capacity of older adults, family members and caregivers to navigate care systems and advocate for innovative approaches to address the growing dementia-related needs in LGBT communities.

LGBT older adults have unique strengths that can help them navigate the complex, fragmented, and often daunting system of health and human services. Among LGBT adults aged 40 to 61, nearly 40% feel that being a sexual or gender minority has prepared them for aging by helping them develop positive personal characteristics and strong support systems (MetLife Mature Market Institute, 2006). Harnessing these strengths requires providers to educate and empower patients to become their own advocates. Challenges navigating the system may be amplified for cognitively impaired LGBT older adults because of difficulty understanding, remembering, and synthesizing complex information. Therefore, providers must also be ready to assist clients, families, and caregivers by facilitating connections across areas of specialty and services.

In order for LGBT communities to harness resources and navigate services addresssing cognitive impairment and dementia, they must have avenues to identify, access, and advocate for solutions that fit their needs. Communities, families, and individuals can build their internal capacity to manage issues related to cognitive decline and shape external supports. Models have been developed in African American communities, for example, to mobilize communities to address cognitive impairment, increase awareness of signs and symptoms, and ensure early screening and diagnosis are culturally competent (Barnes & Bennett, 2014). Such strategies need to be developed and tailored to serve LGBT communities. By building self-advocacy-based relationships with community partners and agencies, LGBT communities can promote awareness of their older adults' needs.

Within LGBT communities, building knowledge, capacity, and supportive infrastructures is essential to ease the burdens of cognitive decline. Communities can be strengthened by creating safe, supportive spaces for socializing among

LGBT older adults living with cognitive impairment, Alzheimer's disease, and other dementias, and their caregivers. Building social networks allows for resource sharing and information about sensitive care, LGBT-affirming providers, and ways to effectively navigate dementia care. Providing such spaces can also create a point of contact for service providers who want to share information and education about health issues and available services.

Conclusion

As a health disparate population, LGBT older adults and their caregivers face heightened risk of unmet needs due to cognitive impairment, Alzheimer's disease, and other dementias. It is imperative that health care and service providers be prepared to ensure sensitivity and inclusivity when serving LGBT older adults and providing outreach and education in these communities. Providers must center clients and their voices in their care. Programs must create welcoming and affirming environments through targeted outreach, recognizing community needs, and building capacity to advocate and develop needed services.

Evidence-based trainings and innovative service models are needed to increase the knowledge and skills of providers. Providers and programs developing these services must seek input from and extend outreach to marginalized segments of the population, including LGBT people of color, bisexual women and men, transgender older adults, and those with limited income and education. By recognizing the diversity of this community, practitioners can also draw on unique sources of strength and resilience of LGBT older adults and their caregivers, who have survived and often thrived despite the adversity they faced. Additionally, researchers must seek to better understand the intersection between LGBT adults' unique risk factors and cognitive impairment, Alzheimer's disease, and other dementias. Longitudinal research, through Aging with Pride, will increase our knowledge of how cognitive decline progresses in LGBT older adults, how and when these older adults and their caregivers are enabled or impeded in accessing supportive services, and how their needs and experiences change over time. With additional information about how cognitive health impacts this population over time, LGBT communities are positioned to plan for their future—a future that is inclusive and responsive to all LGBT older adults, including those living with cognitive impairment, Alzheimer's disease, and other dementias, as well as their caregivers.

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