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Health Disparities among LGBT Older Adults and the Role of Nonconscious Bias

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Abstract

CHJ, in her late fifties and in a long-standing same-sex relationship, had scheduled an appointment with an ob-gyn for bleeding likely related to previously diagnosed uterine fibroids. Her prior ob-gyn had recently retired, and all of her patients had been transferred to the care of another doctor. CHJ was somewhat reluctant to be seen by a new ob-gyn but overcame her trepidation because her prior doctor had highly recommended him. She undressed, donned the requisite gown, and positioned herself on the examining table and in the stirrups with the help of a medical assistant. The doctor entered the room and briefly introduced himself. As CHJ was being examined, the physician looked up and asked if she was sexually active. CHJ responded yes and started to feel discomfited, wondering where this line of questioning was going. The physician said, “Change to your fibroid is large. Haven’t you experienced quite a bit of pain during sexual intercourse with your husband?” CHJ tensed and simply replied, “No, I haven’t experienced any pain.”

This paper describes the significance of key empirical findings from the recent and landmark study Caring and Aging with Pride: The National Health, Aging and Sexuality Study (with Karen I. Fredriksen-Goldsen as the principal investigator), on lesbian, gay, bisexual, and transgender aging and health disparities. We will illustrate these findings with select quotations from study participants and show how nonconscious bias (that is, activation of negative stereotypes outside conscious awareness) in the clinical encounter and health care setting can threaten shared decision-making and perpetuate health disparities among LGBT older adults. We recognize that clinical ethicists are not immune from nonconscious bias but maintain that they are well situated to recognize bias and resulting injustice by virtue of their training. Further, we discuss how clinical ethicists can influence the organization’s ethical culture and environment to improve the quality and acceptability of health care for LGBT older adults.

Historical Context and Life Experience

To better understand and advocate for today’s diverse LGBT older adults, we must recognize and comprehend the current contexts of their lives as well as the on-going impact of the social and historical circumstances in which they have lived. The oldest old are from the “Greatest Generation” (born between 1901 and 1924), the middle old are from the “Silent Generation” (born between 1925 and 1945), and the youngest of older adults are from the “Baby Boom Generation” (born between 1946 and 1964). Each group’s members came of age during or were deeply affected by distinctive historical eras. For example, the Greatest Generation was shaped by the deprivation of the Great Depression, and the Silent

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Generation by the shadow of the McCarthy Era, when same-sex behavior and identities were blatantly and severely pathologized and criminalized. The Baby Boom Generation has been strongly influenced by the civil rights era (1960s) and the Stonewall riots (1969), which ignited the gay liberation movement that allowed LGBT people to begin to emerge from the margins of society.

> As a seventy-year-old said, "In spite of some of the hassles I have had in my life because I am gay, I consider being gay a gift."

Regardless of which generation they belong to, many of today's LGBT older adults spent the majority of their lives concealing their sexual orientation and gender identity from others, including health and social service providers, ever cognizant of their community's historical experiences of discrimination and victimization. As a seventy-two-year-old participant in our study put it, "In the course of many years, since Stonewall, so much has occurred in our struggling attempt to gain respect, understanding and simple rights so freely offered to our straight brothers and sisters. Vigilance and determination are needed to bind our older LGBT constituents and communities. Keeping well, staying well, enjoying life and liberties—here—must never be forgotten."

Caring and Aging with Pride: Select Findings

Lesbian, gay, bisexual, and transgender older adults have been a largely invisible and infrequently studied population. Similarly to other historically disadvantaged or marginalized populations, LGBT older adults are disproportionately burdened by an increased risk of serious illness and disability in contrast to their older heterosexual peers.[1] Critical analysis of the needs and experiences of this population is necessary if appropriate policies and services are to be available to mitigate the health risks of LGBT older adults. The opportunity for healthy aging should, of course, not be predicated on sexual orientation or gender identity.

Directed by Fredriksen-Goldsen, Caring and Aging with Pride, the first national and federally funded research project to examine LGBT aging and health, sheds light on the challenges and strengths of LGBT older adults. The research included a national, community-based collaboration with eleven organizations that provide care and services to LGBT older adults. This project has led to numerous publications and presentations, including *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*, which summarizes the health disparities endured by older LGBT adults, including victimization, psychological distress, disability, discrimination, and lack of access to aging and health services.[2]

Although LGBT older adults are a population "at risk," study findings also suggest striking resilience among LGBT older adults amidst invidious and stigmatizing life experiences. As a seventy-year-old participant said, "In spite of some of the hassles I have had in my life because I am gay, I consider being gay a gift. It has made my life richer and opened so much of the world for me. Of course if I had it to do over again, there are some things I would have done differently but being gay isn't one of them."

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An important and even primary factor in promoting the ability of an individual to successfully manage adversity is a network of supportive relationships. LGBT older adults in this study generally affirm that they have supportive communities; in fact, 89 percent feel positive about belonging to their LGBT communities.[3]

But there was often a high price to be paid to acquire community in this population. Many LGBT older adults came of age when nonheteronormative behavior was criminalized. For many there were stiff penalties to be incurred, including the possibility of incarceration, violence to one's person, loss of personal freedom and of the ability to support oneself, and the inability to love and befriend whomever one chose. Eighty-two percent of LGBT participants report having been victimized at least once, and 64 percent report experiencing victimization at least three times in their lives.[4] Lifetime experiences of discrimination and internalized heterosexism are significantly associated with poor mental health, physical health, and disability among LGBT older adults.[5] Not surprisingly, nearly four in ten LGBT participants have experienced thoughts of suicide at some point in their lives.[6] The opportunity to develop a community and actualize social support entails risky self-disclosure, but nondisclosure of sexual orientation risks isolation and loneliness. Some study participants plan never to reveal their sexual orientation or gender identity, and others will permit disclosure of their identity only following their death. An eighty-eight-year-old participant revealed, "I am not aware that anyone close to me knows or suspects my sexual orientation. My son once hinted at it but not in recent years. At my death, they will probably find tell-tale clues."

Too few LGBT older adults are sanguine about accessing high-quality health care. Nearly 15 percent of LGBT older adults participating in the study reported that they were fearful about accessing health care services outside of the LGBT community, and nearly 13 percent reported that they were denied health care services or provided with inferior care as a result of their sexual orientation or gender identity. While most LGBT participants have disclosed their sexual orientation or gender identity to their primary care physician, nearly one-quarter have not revealed either aspect of their identity to their physician. Those LGBT persons eighty or older were more likely to keep their identity a secret from their physicians. A participant said, "I was advised by my primary care doctor (at my HMO) to *not* get tested there, but rather do it anonymously, because he *knew* they were discriminating."

Failure to disclose sexual orientation or gender identify may have adverse health consequences for LGBT older adults, such as a delay in diagnosing a serious medical problem.[7] Caring and Aging with Pride findings concerning LGBT older adults' antipathy toward the health care system, fear of accessing care, and the difficulty of revealing sensitive but material information suggest that shared decision-making during the clinical encounter is likely to be compromised, thereby contributing to the perpetuation of health inequalities among LGBT older adults. Shared decision-making presumes that the patient is willing to discuss their values, their preferences, and intimate details about themselves openly with their physician in order to develop a plan of care that is acceptable to the patient. Shared decision-making aims to promote patient autonomy, given an understanding of patient autonomy as relational, its expression determined by the interplay between the patient and provider within the broader context of the health care delivery system. The

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relationship must be informed by trust and a belief in the clinician's (and institution's) benevolence—especially since marginalized patients may be more sensitive to what they have to lose rather than what they have to gain in the clinical encounter. Trust in this context may be defined as a "psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behavior of another."[8] Vulnerability, as this study demonstrated, is actively avoided by many LGBT older adults to prevent further victimization, including denial of health care equivalent to that received by their heterosexual peers.

Nonconscious Bias and Health Disparities

An important step in eliminating avoidable inequalities and in creating an expectation of trust and comfort across health care encounters is to acknowledge that non-conscious stereotyping of LGBT older adults (and other marginalized groups) persists in the health care delivery system and that these biases contribute to health disparities. Medical professionals' diagnoses and treatment of their patients can also be influenced by nonconscious bias,[9] itself an important contributor to health disparities.

When heterosexism is internalized, clinicians (and other members of the health care team) may hold and act in accordance with anti-LGBT stereotypes and attitudes. Nonconscious stereotyping may manifest in acts of victimization and discrimination, as, for example, when a transgender patient is denied care or when a hospital fails to allow a same-sex life partner to be at the patient's bedside in the intensive care unit or refuses to release the body of the loved one to the partner at the time of death. It also manifests as beliefs that exist below the level of awareness (for example, seeing nonheteronormative sexual orientation as "disordered," "immoral," or "mutable") and therefore inadvertently leads to negative behaviors such as requesting to be relieved of caring for a patient on conscience grounds, ignoring the patient's loved ones, or joking about the patient with other staff members).[10] Unaddressed biases also manifest in the form of "microaggressions"—"brief, daily assaults on minority individuals, which can be social or environmental, as well as intentional or unintentional."[11] All-too-common microaggressions include assumptions that one is married to a person of the opposite sex; being asked, based on this assumption, what one's husband's or wife's name is; being asked to complete demographic forms that fail to capture the relationship possibilities of gay persons, such as "partner" or "domestic partner"; having one's life partner referred to as a "friend"; and directing communication to the patient's adult children while ignoring and isolating the life partner. These insults and invalidations can have deleterious effects on LGBT older adults' health and decisions about whether services are used.

Although flagrant discrimination and overt bias may be waning within many regions of the United States, nonconscious bias continues to shape our attitudes, beliefs, and behavior. Many of us would find it personally repugnant to find that we harbor biases that we consider objectionable when observed in others and that we undoubtedly fortify group advantages and contribute to group disadvantages— being unwitting accomplices to the reinforcement of systematic injustice. However, a large body of empirical evidence demonstrates that we are all prone to nonconscious bias by virtue of a lifetime of exposure to social and cultural

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attitudes about, among other things, age, gender, race, ethnicity, sexual orientation, and gender identity.[12] Evidence also shows that nonconscious bias activates stereotypes that influence the judgment of even low-prejudiced, well-intentioned, and egalitarian individuals.[13] Although low-prejudiced individuals are more likely to be able to catch and control explicit biases, implicit biases are still apt to "leak out" through nonverbal communication (eye contact and speech errors, for example) and avoidance behaviors (limiting time, failing to shake hands, turning away) that convey unease or frank dislike.[14]

Nonconscious bias creates a "catch 22" for LGBT older adults when they are considering whether and when to disclose their sexual orientation or gender identity to their physician or other caregivers—especially given the historical context of concealment and victimization discussed earlier. On the one hand, not disclosing may have health consequences if sexual orientation or gender identity is material to an individual's diagnosis and treatment. On the other hand, disclosing may activate stereotypes in caregivers that adversely impact the patient's health care or make the patient feel uneasy, uncomfortable, or afraid. LGBT older adults are likely to encounter nonconscious bias related to both their age and their sexual orientation or gender identity. Ageism operates in a similar way as heterosexism; both are imbedded in personal and cultural beliefs, reinforced through doctrine, education, and the media.[15]

> Microaggressions by health care workers include communicating directly with the adult children of a patient while ignoring his or her life partner.

Enduring Impact of Bias

We should also recognize the long-term and even generational impact that negative experiences may have on LGBT older adults' health. As Fredriksen-Goldsen and colleagues confirmed, many LGBT older adults have had negative experiences when attempting to access health care or during their care and treatment, and these negative experiences are likely to influence their subsequent interactions with the health care community and may lead even to the avoidance of needed care.[16]

This observation is consistent with the well-studied phenomenon of negativity bias in human cognition. Negativity bias, or positive negative asymmetry, is the observation that negative experiences are more salient, potent, and dominant than positive experiences.[17] This concept is well expressed by the aphorism that "a spoonful of tar can spoil a barrel of honey but a spoonful of honey does nothing for a barrel of tar."[18] Negative information is cognitively processed repeatedly and over a longer period and contributes to a final impression that is more resistant to disconfirmation through past or subsequent positive information. Negative experiences are often shared with others, compounding the reach and durability of negative information and experiences.[19] Within a context of prior negative experiences, including victimization, discrimination, or just pure insensitivity, it is easy to understand why LGBT older adults may be reluctant to access health care services or fully trust their physician and other caregivers.

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A Role for Ethicists

Reducing health disparities for LGBT older adults in the health care setting requires a burning platform for change and one in which clinical ethicists may play a modest role. Clinical ethicists are well positioned to be a voice for and to encourage the voice of LGBT older adults, a population that is all too often silent or silenced—whether in the boardroom, the clinic, the classroom or at the patient's bedside. Examining unexamined assumptions and rendering implicit values explicit are the bread and butter of the clinical ethicists' craft, skills essential to making visible and then diminishing differential and unjustified burdens on a stigmatized population.

Clinical ethicists in a health care setting typically provide ethics consultation services and ethics education and develop or inform organizational policies. Clinical ethicists can review their consultation records and identify themes related to LGBT issues or query clinical staff about ethics issues that may arise when caring for LGBT older adults. These issues, whether identified from consultation records, surveys, or other administrative data (such as patient complaints) or qualitatively through discussion with staff members and, of course, patients, can form the basis of ethics education (and of more systems-oriented approaches such as quality improvement) that can occur in management meetings, in the clinical classroom, during ethics rounds, or even during consultations.

Clinical ethicists may also play a role in shaping the organizations' culture through policy development. Policies can help drive practice toward more equitable health care practices, including offering a more welcoming environment and culture. Visitation policies that are inclusive of an LGBT patient's spouse or domestic partner are one example. Others include nursing home policies that are supportive of self-determined intimate relationships between LGBT older adults or that support transgender older adults in dressing as they see fit. Finally, clinical ethicists who allow for the existence of their own unwanted biases, seek training in implicit bias and its reduction, and are culturally competent in LGBT aging issues will be uniquely positioned to advocate for a hospitable institutional culture that fosters dignity, autonomy, and justice for LGBT older adults, bringing benefit to individual patients but also fulfilling the ethical imperative to improve outcomes for communities of patients.

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