Health Care Inequalities Surrounding LGBTQ Elder Care

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Since Jan. 1, 2011, approximately 10,000 baby boomers (born between 1946 and 1964) turn 65 each day (Orel, 2013). Between 2000 and 2010, the population of Americans 65 and over increased by about 15 percent compared to the overall U.S population, which increased at a rate of 10 percent (Werner, 2011). Recent population-based surveys also indicate approximately 3.5 percent of adults in the U.S. identify as lesbian, gay, or bisexual, and 0.3% of adults identify as transgender. This equates to nearly nine million people in the lesbian, gay, bisexual, transgender and queer (LGBTQ) community (Ard & Makadon, 2012), of whom 1.5 million are over the age of 65 (Sage general facts & discrimination, 2012-2015). Studies show these elders are fearful for their safety as they age and require more care.

LGBTQ baby boomers, also known as "Stonewall seniors" (in honor of those who fought for gay rights and equality in the 1960s) are considered to be the first "out" generation in LGBTQ history (Fitzgerald, 2013). Stonewall Seniors are now retiring, becoming frailer, and beginning to think about their needs as older adults. This includes the possibility of having to depend on others for care. However, many LGBTQ seniors are not seeking care out of fear that direct care workers, who provide home-based personal care, might discriminate against them. In addition, they also fear possible abuse, or the unwanted intrusion of a religious caregiver who requests the person needs to ask forgiveness for their homosexual behavior.

The purpose of this study is to explore health care inequalities for LGBTQ elders. There is a disturbing trend among LGBTQ elders of avoiding the doctors' office altogether, for fear staff do not have the sensitivity training necessary to manage their needs (Fitzgerald, 2013). As a result, these

individuals feel the need to hide their sexual identity and appear "straight" or avoid seeking critical medical care entirely (Maddux, 2010). If an LGBTQ elder needs nursing home care, there is the added fear of leaving a loved one in the care of nursing home staff who may discriminate against them or be abusive.

LGBTQ individuals are more likely to age alone as opposed to heterosexual elders (Brennan-Ing, Karpiak, & Seidel, 2011; Thurston, 2009). They often have a minimal support network and may have lost many family members and friends after choosing to reveal their sexual orientation or gender identity. Frail, older LGBTQ adults often die at a younger age as compared to their non-LGBTQ peers due to lack of support and proper medical care. What is even more troubling is a study by Ward, Rivers, and Sutherland (2012) that revealed some transgender individuals are planning to commit suicide before getting to the point of needing care from medical professionals who they believe do not understand their needs and/or lack the diversity training needed to be comfortable caring for older LGBTQ adults.

It is critical that all agencies serving the elder population are welcoming to LGBTQ individuals. It begins with raising awareness of the issues with eldercare agencies. Training also needs to be provided to all medical and direct care staff in order to develop cultural competence and sensitivity when dealing with the unique needs of the LGBTQ elder population. These steps are crucial to enable Stonewall seniors to reduce their fear and confidently seek medical and in-home care as they age. No elder should be alone and without the compassion and quality care that is needed in the later years of life. To better understand this social crisis, our study will explore the following question: What are the primary concerns of LGBTQ individuals related to gaps in the health care system surrounding the needs of aging members of their community?

REVIEW OF LITERATURE

The purpose of this study is to identify gaps in care, where medical care and education are lacking, and what needs to be done within the health care system to better support the under-served LGBTQ elder population. It is important to note that, although LGBTQ is inclusive of all individuals who identify as other than heterosexual, the needs of each group are unique. Transgender people do not identify with the gender assigned to them at birth and feel they were born in the wrong body. This has been known to cause contentious feelings among transgender people who have pointed out that gays and lesbians cannot identify with the inner turmoil of being

transgender (Brydum, 2015). For the purpose of this study, however, we will examine LGBTQ needs globally.

Several studies examined elder care services as they pertain to LGBTQ culture. They pointed to an alarming trend—no discipline within the medical field receives sufficient training in the unique care needs of LGBTQ elders. This lack of education creates an unfortunate domino effect. Insufficient training of medical workers results in inadequate services along with staff that lack empathy and knowledge of LGBTQ issues. Consequently, this leaves LGBTQ individuals with a limited number of clinics where they might receive informed quality care. The deficiency of care, in turn, leads to health care avoidance behaviors and eventually results in health complications, comorbidities and, in many cases, premature death.

In 2012, LGBTQ individuals were identified as an at-risk population with regards to not having access to quality health care. Fredriksen-Goldsen et al., (2014) who studied health disparities of older adults in the LGBTQ community also identified LGBTQ individuals as a marginalized population with high risk factors for poor health, disability, and untimely death.

Orel (2013) examined the needs and concerns of LGBTQ older adults through the use of qualitative and quantitative methodology. She conducted focus group discussions with 26 lesbian, gay, and bisexual individuals (she was unable to identify transpersons despite her efforts at recruitment and inclusion). Her study identified seven areas of importance to LGB individuals, including health care, legal issues, institutional/housing, spiritual needs, family issues, mental health, and social concerns.

Consistent with past studies, Orel (2013) also demonstrated that the numerous health disparities in the LGBTQ culture are predominantly the result of discrimination, which increases stress and leads to poor health. There also are the issues of the impact of limited access to health care (Orel, 2013), the disproportionately higher risk for violent hate crimes, sexually transmitted diseases, and poor mental health in the LGBTQ community (National LGBTQ Task Force, 2016; Orel, 2013).

Rogers, Rebbe, Gardella, Worlein and Chamberlin (2013) noted that as a result of past discrimination and insensitivity from service agencies, LGBTQ elders are reluctant to disclose their sexual orientation/gender identity or to seek services from non-LGBTQ agencies. They conducted a study to look at the effect of having older adults from the LGBTQ community conduct training panels for potential service providers. Trainings were offered by the Gay and Gray Program (GGP) out of Portland, Ore., which provides

LGBTQ elders with, among many other servics, health and wellness education. The panel trainings focused on issues of concern to older LGBTQ adults, with the goal: "To help the participants reflect on their biases and attitudes toward older LGBTQ adults" (p. 585). The study concluded that panel discussions were successful in raising awareness, putting a face on LGBTQ issues, facilitating self-reflection, promoting deeper understanding, fostering acceptance, and garnering empathy.

Another study by Lim and Bernstein (2012) examined the need to promote awareness of issues among older LGBTQ adults in an undergraduate nursing program. Not only did the study reiterate the critical need for more training of medical professionals, but it sought to answer the question of how we gain the trust of LGBTQ baby boomers. Boomers came out of the closet and fought for gay equality during a time of intolerance, a time when people were deemed mentally ill because of their sexual orientation (Lim & Bernstein, 2012). Even today, gender dysphoria continues to be a diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The same authors noted in their study of 150 medical schools that the average number of hours dedicated to LGBTQ topics was five. It is projected that at the height of the aging boom there will be 88.5 million people over the age of 65, and LGBTQ elders will comprise one out of every 13 elders in 2050. Clearly, five hours of medical training is insufficient to meet the needs of the aging LGBTQ community (Lim & Bernstein, 2012).

Wood and Conley (2014) reviewed the impact of being lesbian, gay, bisexual, or transgender on religious and spiritual identity. It is the religious negativity associated with being LGBTQ that makes this an important social work issue. The authors broke down the types of religious and spiritual abuses that may be perpetuated by members of the congregation, whether in a leadership role or as peers. Three such abuses were: leadership representing God, spiritual bullying, and sexual microaggressions. The consequence of such abuse may result in feelings of depression and anxiety and can have a negative impact on health and well-being (Wood & Conley, 2014).

A study by Hughes, Harold and Boyer (2011) looked at the level of awareness of LGBTQ issues among elder service providers. The majority of the sample (n = 87) consisted of heterosexual, white women with an average age of 46. Sixty-eight percent reported being 'very comfortable' assisting older LGBTQ adults, and 31 percent reported being 'very knowledgable' about Medicare and Medicaid as they relate to LGBTQ issues.

The majority, however, rated themselves as only "somewhat knowledgable" on such LGBTQ matters as legal and financial concerns, barriers to service, and medical issues (Hughes, et al., 2011). When asked if they wanted further training on LGBTQ issues, 50 agencies requested additional training while 29 did not (Hughes, et al., 2011).

Porter and Krinsky (2013) examined whether LGBTQ trainings result in positive change within elder service agencies. Their findings demonstrated an increase in knowledge of public policies and LGBTQ resources. The training also increased participants' beliefs that intakes should include questions related to sexual orientation and gender identity as it can lessen the perception by LGBTQ individuals that medical providers are not sensitive to their needs (Porter & Krinsky, 2013). The training also improved service providers' comfort level with the idea of having a patient "come out" to them. On the other hand, training was associated with less confidence in the service providers' ability to meet the needs of a transgender person. Porter and Krinsky (2013) surmised that with new learning came an awareness that the providers lacked both the knowledge and skills to competently meet the needs of a transgender person.

Lastly, Brennan-Ing, Karpiak & Seidel presented a comprehensive report through the AIDS Community Research Initiative of America (ACRIA) in 2011. Their sample included just over 200 individuals with an average age of 60. Seventy-one percent were men, 24 percent were women, and 5 percent identified as transgender or intersex (Brennan-Ing, Karpiak, & Seidel, 2011). The purpose of the study was to identify health and psychosocial needs of LGBTQ elders, and to examine similarities and differences between LGBTQ persons with and without the HIV virus. Findings showed the rate of severe depression was almost double in HIV positive persons as compared to those that were HIV negative. There also were sigificantly higher levels of alcohol and substance abuse in the the HIV positive group.

Given the results of the aforementioned studies, the current study will seek to answer the following questions: What are the primary concerns of LGBTQ individuals related to gaps in the health care system for aging members of their community? Are there perceived gaps in medical care for LGBTQ persons? What causes avoidance behavior of LGBTQ individuals regarding medical care? What needs to be done to educate medical professionals on the needs of aging LGBTQ persons?

METHODOLOGY

Using a qualitative design, the researcher's objective principle question was "What are the primary concerns of LGBTQ individuals related to gaps in the health care system for aging members of their community?" The qualitative approach taken to explore this question was a phenomenological analysis. The researcher initially proposed purposive sampling—the deliberate process of selecting respondents based on their ability to provide the needed information (Padgett, 2008). In order to recruit participants, correspondence was sent to several agencies that serve the LGBTQ elder population to inform them about the research study and its purpose. In the interest of privacy laws, the agencies were not asked to refer people to the researcher, but to provide the researcher's contact information to anyone they felt would be willing to participate.

Two agencies returned correspondence indicating they could not assist in the study, and one agency responded by inviting the researcher to attend a monthly LGBTQ luncheon. Although unable to make the luncheon, the researcher made a flyer that was passed out by a volunteer. The volunteer reported that several attendees took a flyer; however, the researcher received no response. Convenience sampling, along with snowball sampling, were then used to identify four study participants selected based on sexual orientation. Two were a married male couple, aged 36 and 55. Although younger than originally planned for the study, the 19-year age difference had led to discussions on future planning. They were recruited through text message and are friends of the researcher. As required by snowball sampling, they were asked to refer the researcher to anyone they knew in the LGBTQ community that might want to participate in this study.

The other two participants were women who identify as lesbians. One is age 58 and has been in a relationship with her wife more than 25 years and married for approximately eight of those years. The other is age 78 who lost her wife earlier this year after 30 years together. The participation of these women was valuable because, not only did they provide a different perspective than the men, but according to the research, older lesbians are more likely to hide their orientation (Fitzgerald, 2013). As one of the women was also the caregiver for her wife and took care of her with the assistance of hospice in the home, she was able to give a unique perspective on that experience. The participants will be referred to as P1, P2, P3, and P4.

Data collection for qualitative research typically consists of three modalities: observation, interviews, and review of documents (Padgett, 2008).

Each participant was offered their choice of locale for the interview: in their home, the researcher's home, or a public venue. All of the interviewees chose the researcher's home. Each interview occurred at the dining room table in the late afternoon. There was one meeting per interview and the interviews were recorded, each lasting between 30 to 60 minutes.

To ensure protection of participants' rights and dignity, each signed an ethics consent form outlining the purpose of the study and providing contact information for the researcher, the professor, and an LGBTQ hotline. Participants were assured they did not have to answer any question with which they were uncomfortable. Each participant was compensated for their time with a $5 gift certificate and were offered a copy of the final report. Careful preparation allowed the interviewee to assist the researcher in entering their world. The researcher asked the same-sex male couple to watch the documentary, *Gen Silent,* by director Stu Maddox (2010), in order to bring awareness to this social crisis. The researcher also gave each interviewee some background on why this project has taken shape and why it is critical to promote awareness among both older and younger LGBTQ persons.

The beginning of the interview focused on the participants' sexual orientation and then each was asked to describe when they came out to friends and family. These questions were designed not only as a benevolent introduction to how they each identify, but also to better understand whether their experience of coming out was a positive or negative one. Research has shown that people who do not have a good support network are more likely to experience health disparities (Ard & Makadon, 2012; Fitzgerald, 2013).

Subsequent questions explored whether the participants had any concerns or discomfort when seeking medical care and whether they felt their doctor's office was LGBTQ friendly. These questions were intended to ascertain any perceived gaps in the health care system related to cultural competence and whether steps are taken at clinics to demonstrate inclusion. Studies indicate there is limited awareness of LGBTQ issues within the health care system (Hughes, et al., 2011), that clinics do not always promote inclusion [Worcester LGBTQ Elder Network (WLEN); Brightstar Care, 2015], and that there is very limited LGBTQ education provided in medical schools to prepare future care providers for management of these issues (Lim & Bernstein, 2012).

Further questions explored participants' feelings regarding nursing home placement and whether direct care workers are equipped to deal with

LGBTQ aging issues. As Stu Maddox (2010) demonstrated in *Gen Silent*, if an LGBTQ person perceives a lack of understanding, or the potential for discrimination within a health care setting, they are far less likely to seek medical care until a crisis occurs. Studies have also shown that LGBTQ persons are less likely to have health care insurance (Gates, 2014) and less likely to receive equitable health care (Fredriksen-Goldsen, et al., 2014).

Data analysis involved analyzing the recorded interviews to explore themes and patterns. Other analysis included observations of body language during the interviews, as well as a review of peer-reviewed scholarly work on this topic.

FINDINGS

Several core themes emerged from the data. The first theme identified was *emotional/coping*. Within this theme, several issues were discussed, including addiction, depression, fear, courage, and denial. The emotional distress centered on the realization of being gay and the eventual acceptance of it. Two participants struggled with addiction while another dealt with their spouse's addiction. All four indicated they had emotional difficulty after the initial realization that they might be gay. Each participant also displayed remarkable courage when making the decision to come out to family and friends, knowing it may well have resulted in the loss of some of their closest relationships.

Another theme that emerged was the *social impact* surrounding the sexual orientation of each study participant. This theme encompassed religion, support networks, romantic relationships, marriage, family, friends, neighbors, and career. Religion was not initially part of the interview questions, but was subsequently incorporated after the first two interviewees raised this as a significant area of focus.

P1 struggled mightily on a religious level, feeling he was an "abomination" and feared God would hate him for being gay. He sought to be "cured" by attending church. He hit a turning point in his journey, however, after experiencing what he described as the hand of God resting on his shoulder and he heard God tell him "It is okay. You are my son and I love you just the way you are." He finally felt a sense of peace and no longer believed God hated him.

P2 stated his belief that "God makes people who they are supposed to be. I don't think I ever struggled religiously with being gay." P3 and P4 both stopped going to church. P3 stopped because the Catholic church has

historically been against homosexuality, and P4 became "turned off" after she approached a Catholic priest who appeared to have no interest in offering her support or comfort and "did not seem to want to be bothered." All four participants still have faith/spirituality, and P3 is considering committing to the Unitarian church; a religion that is accepting of and welcoming to LGBTQ individuals.

Another theme identified was *LGBTQ considerations*. This was comprised of: the age of participants when they realized they were gay, coming out, sexuality, LGBTQ in sports, transgender, cross-dressers, and Provincetown. One interesting finding surrounded the age of coming out to family and friends. Though both males realized they were gay before the age of 10, neither came out until they were almost 30, and both came out to the women in their family first. Both of the female participants realized they were lesbian during their teenage years, one came out around age 16 and the other at 21.

Subsequent themes included *negativism*, *advocacy/resources*, *future planning*, and *lifestyle*. The theme, *future planning*, addressed medical care, nursing home placement, caregiving, long-term care insurance, and accepting help. An interesting and unexpected finding was that no inter- viewee reported concerns about going to the doctor's office. It was noted, however, that none of the medical offices were outwardly LGBTQ-friendly, meaning there was no literature, marketing materials, posters, or other resources that target the LGBTQ population for the purpose of inclusion and engendering a welcoming atmosphere.

Participants were evenly divided when asked whether they have concerns related to nursing home placement. P1 and P3 expressed concern with having to live in, or put their spouse in, a nursing home, while P2 and P4 did not. Participants who expressed concern stated they were troubled by the lack of education and sensitivity training for medical staff and direct-care workers regarding LGBTQ issues. Those that did not express concern about nursing home placement stated they have "no qualms about it" and P4 stated "I try to joke with people…If they come aboard on my side, then great, but if not, I would know my place, but would not let them walk over me."

Finally, the theme of *advocacy* revealed issues such as death with dignity, housing for LGBTQ persons, policy change, resources, and important issues for non-LGBTQ medical professionals to know. An important finding here relates to three of the four interviewees who acknowledged they would

prefer to live in LGBTQ housing. The fourth was ambivalent about housing. The key reason for preferring LGBTQ housing was not only for inclusion and comfort, though that was primary. Other reasons that surfaced had to do with activities of common interest, as well as providing a "safe haven" for people from other cultures or countries which may imprison or execute a person for being homosexual.

When asked if housing for LGBTQ would be isolating, one participant challenged the researcher, asking "If a facility is not LGBTQ friendly, [that person] is already isolated. If I had to go back into the closet, how much more isolated can you be? If the staff is either gay or empathetic to the struggles these people have been through, then they will be in a place of love and support and that will keep you free of isolation." Two of the interviewees also made the suggestion that this type of housing would not need to be exclusively for LGBTQ individuals and that they would welcome integration of non-LGBTQ, but with the understanding that it would be an open facility.

Some words of wisdom that participants felt non-LGBTQ medical staff should be aware of included the following statements: "Being gay is not a disease that you catch; it's something that you're born with." "Just be aware and open and not so close-minded. Don't assume, it is basic social work. We meet the clients where they're at." "We're like everybody else. Be sensitive to differences, whether they're gay or a minority of some other type." "Just be yourself and let us be ourselves."

IMPLICATIONS AND CONCLUSION

The findings of this study were consistent with other studies conducted over the past five years. There are several changes that need to take place to improve care to the LGBTQ elder population, which continues to be underserved (Lim & Bernstein, 2012). The first step to minimize discomfort among medical professionals is education. Policy changes are needed to ensure that LGBTQ training is mandatory and recurrent (at least annually) for health care workers. Education promotes awareness which, in turn, creates empathy and understanding (Rogers, et al., 2013) .

Despite the finding that none of the study participants expressed discomfort when visiting their medical doctor, what did emerge is the belief that medical clinics have a long way to go in the creation of an LGBTQ-friendly atmosphere. Orel (2013) concluded that "one of the greatest obstacles [continues to be] the level of homophobia and heterosexism within the culture" (p. 70).

Additional considerations that should be addressed by clinicians is the impact the loss of religious and spiritual identity has on LGBTQ individuals. Religious impact was brought up by each of the participants in this study and it clearly played a role in the ability for some to cope with and come to an acceptance of their homosexuality. The loss of a religious and/or spiritual identity may not only adversely impact emotional well-being, but it also puts LGBTQ individuals at a higher risk of abuse by church members (Wood & Conley, 2014).

The small sample size of the study is a limitation. Only one interviewee was over the age of 65, which could account for why only half the sample expressed concerns related to medical care. Younger LGBTQ individuals appear more open and less concerned about conventionalism. The researcher also was only able to recruit individuals who identify as gay and lesbian, and was not able to recruit a transgender individual. Due to participants for this study being collected through convenience and snowball sampling, it is also likely that they overrepresented people who are more open to talking about their experiences.

Further research should be done with health care agencies to explore why trainings on LGBTQ issues are not regularly provided to staff. Studies on this topic have only spanned the last five to 10 years. Further studies of a longitudinal nature may be necessary to ascertain if systematic LGBTQ trainings do effectuate positive change in the long-term attitudes and empathy of health care workers. Porter and Krinsky (2013) agree that supplemental trainings would be necessary and should not be just a singular curriculum. It is again important to note that, although the LGBTQ acronym globally considers all individuals that identify as queer, each subcategory of the acronym carries its own unique needs and cannot be mistaken for a "one-size-fits-all" philosophy. Their needs are shaped by many factors, including race, ethnicity, age, and socioeconomic status (Lim & Bernstein, 2012).

Today's youth appears to be playing a significant role in the shift in attitudes and biases towards LGBTQ individuals. This shift has taken place over the last 12 years, since Massachusetts became the first state to legalize gay marriage (Jones, Cox, & Navarro-Rivera, 2014). The millenial generation seems to be less accepting of the heteronormative codes of the late 20th century mainstream culture and more people now approve of gay marriage than ever before (Jones, et al., 2014).

This shift, however, is still in its infancy. Until today's youth begins

taking care of our seniors in the next 20-30 years, it is more important than ever to heed the words so eloquently spoken by an interviewee from this study. When asked what is important for non-LGBTQ persons to know, he responded "Do you really want to cause these people more pain than they have already experienced? More understanding leads to more empathy, compassion, and patience. Understand my struggle and walk in my shoes before passing judgment on me."

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