

RETIRING TO THE CLOSET: SOUTHERN LGBT ELDERS & LONG-TERM CARE

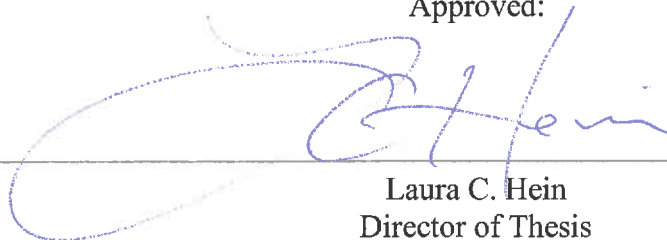
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Thesis Summary

This group senior thesis consists of a quantitative survey and qualitative phone interviews conducted with lesbian, gay, bisexual, and transgender (LGBT) older adults living in the Deep South (NC, SC, GA, AL, MS, LA, FL). Through these survey responses (n=728 complete surveys) and phone interviews (n=5), this senior thesis seeks to identify Southern LGBT older adults' perspectives of and experiences with long-term care (LTC), to target regional gaps in the existing literature, and to update the existing literature after the legalization of marriage equality. The survey portion of this senior thesis asked participants about their demographic information, level of outness, social support system, everyday discrimination experiences, perceptions of the political climate, consideration of a healthcare power of attorney, consideration of LTC services, perceptions of discrimination in LTC, willingness to utilize certain LTC services, fear of LTC services, and direct and indirect experiences with LTC. The phone interviews asked participants about their perception of differences in LTC receptiveness for LGBT and non-LGBT residents, perceptions of Southern LTC services, experiences with LTC, and recommendations for making LTC more inclusive. From these responses, this senior thesis found that Southern LGBT older adults perceive LTC services, particularly those offered in the South, as discriminatory. However, they were also relatively willing to utilize some types of LTC services. The researchers in this study hope to further analyze the correlations between variables in this study and produce two manuscripts from this data. Future studies in this field can also look at whether negative perceptions lead to reticence to utilize care, the effects of discrimination in LTC on LGBT older adults, and the relationship between perceptions and lived experiences in LTC. By identifying how LGBT older adults perceive LTC services and by

recommending ways to make LTC services more inclusive of LGBT identities, this senior thesis hopes to improve the quality of life for LGBT older adults.

Abstract

Long term care (LTC) is a concern of older LGBT adults because of the risk of discrimination from care providers and other residents. However, prior studies on this topic have failed to attract large samples from rural and southern areas and were primarily conducted before the legalization of same-sex marriage in 2015. This study seeks to identify the perceptions and experiences that Southern LGBT elders (aged 50 and older) have regarding LTC services and facilities and to address the limitations of current research on this topic. This mixed methods study gathered perceptions of and recommendations for LTC from LGBT older adults who live in the Southern U.S. (NC, SC, GA, AL, MS, LA, FL). The study consists of a quantitative online survey (n=728) and qualitative one-on-one interview data (n=5). Even with a cohort of LGB older adults with relatively low levels of everyday discrimination and high levels of outness, these Southern LGB older adult participants believed that residents, providers, and staff may engage in discrimination against individuals based on sexual orientation and/or gender identity. Despite these beliefs, participants were relatively willing to use certain types of LTC services. A majority of them also held negative perceptions of the South and the LTC services provided in the South. Participants recommended the creation of LGBT-specific facilities, the implementation of diversity training for providers and staff, and an increased number of LGBT providers in order to improve inclusivity within LTC services. The information gathered can be utilized to create safer, more welcoming spaces for older LGBT adults who need LTC services.

Introduction

An estimated one to three million adults aged 50 and older self-identify as lesbian, gay, bisexual, or transgender (LGBT) in the United States, and this number is expected to double by 2030 (Cahill, South, & Spade, 2000; Fredriksen-Goldsen & Kim, 2017; Services & Advocacy for Gay, Lesbian, Bisexual, & Transgender Elders [SAGE], 2010; U.S. Census Bureau, 2014). Compared to their non-LGB counterparts, LGB older adults are at a higher risk for a variety of negative health outcomes including disability, poor physical health, and poor mental health (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013b). Community-based studies on the health of transgender older adults also shows higher risks of poor general health, disability, and mental distress than cisgender sexual minority older adults (Fredriksen-Goldsen et al., 2013a).

Lifetime experiences of discrimination can even exacerbate certain negative health outcomes and discourage the utilization of healthcare services among the LGBT population (Cahill, South, & Spade, 2000; Espinoza, 2014; Fredriksen-Goldsen et al., 2012; Fredriksen-Goldsen et al., 2013b). Factors such as lifetime victimization, financial barriers, and internalized stigma can lead to a higher risk of negative health outcomes among LGB older adults, including poor general health, disability, and depression (Fredriksen-Goldsen et al., 2012). Although LGBT older adults have higher risks of negative health outcomes, they may also avoid or delay health care out of fear of discrimination (Cahill, South, & Spade, 2000; Espinoza, 2014). Compared to cisgender sexual minority older adults, transgender older adults have an increased incidence of victimization and internalized stigma. Furthermore, the perceived prejudice around gender identity can cause transgender individuals to have internalized stigma,

lack social support, and fear accessing health services (Fredriksen-Goldsen et al., 2013a). However, increased social support and social network size can be protective factors to these health outcomes in the LGB population (Fredriksen-Goldsen et al., 2012). In addition to the experiences of prejudice and discrimination that LGBT older adults face as a result of identifying as a sexual minority, some LGBT individuals may also experience prejudice and discrimination that further affects their health as a result of their other identity categories and sexual minority subgroups.

Although increased social support and social network size is a protective factor for LGB older adults' health, there are concerns that LGBT older adults will not have social networks and caregivers to assist them with their health problems while aging. Family members provide 80% of the long-term care in the United States, but LGBT older adults are less likely to have relatives upon whom they can rely, instead relying on friends and community members that are referred to as "families of choice" that are not always legally recognized (Healy, 2002; SAGE, 2010). LGBT individuals also have a high likelihood of living alone, which is a risk factor for isolation (Cahill, South, & Spade, 2000; SAGE, 2010). LGBT older adults may even feel estranged from traditional aging programs because of homophobia, and the LGBT community because of ageism (Altman, 1999; SAGE, 2010). Moving into LTC facilities to receive caregiving services may further estrange LGBT individuals from their LGBT community support systems, partially because LGBT individuals may have to hide their identities when relying on caregivers (Brotman, Ryan, & Cormier, 2003; Walker, Curry, & Hogstel, 2007). Because of the lack of social support systems for LGBT older adults while aging, some LGBT individuals and organizations are concerned about how this population will be cared for in the future.

Despite the growth in the amount of LGBT adults over 50 and the increase in health risks for this population, research about the health and healthcare of LGBT older adults is limited. The Institute of Medicine (2011) has even recognized LGBT older adults as an at-risk and underserved population. The experiences of LGBT older adults and long-term care (LTC) services is especially underresearched. However, the existing research on LGBT individuals' perceptions of and experiences in LTC indicates that LGBT individuals may fear prejudice and discrimination in LTC services. Johnson et al. (2005) found that 73% of participants in a community survey of LGBT individuals believed that discrimination existed in retirement care facilities that are not specific to LGBT individuals. These perceptions' differed based on participants' age, gender, community size, and income level (Johnson et al., 2005). The National Senior Citizens Law Center (NSCLC) et al. (2010) found that only 22% of LGBT older adults participating in the survey felt comfortable with either themselves or their loved ones being "out" in a LTC setting. Participants from this survey also reported 853 total instances of mistreatment, 124 of which were reported by LGBT older adults. Furthermore, Stein, Beckerman, & Sherman (2010) found that lesbian and gay elderly participants in their qualitative study frequently cited fear of discrimination in LTC services from providers and residents. These findings partially illustrate the fears that LGBT individuals face while considering LTC options for themselves or their loved ones, and the concerns LGBT older adults face when entering LTC.

However, these existing studies surveyed participants primarily from northern and eastern areas of the United States. Therefore, regional differences in perspectives of and experiences in LTC are not taken into account, and the perspectives of Southern LGBT older adults may be neglected. This lack of regional specificity is found in much of the literature on

LGBT individuals. Although 35% of LGBT individuals live in the South compared to other areas of the United States, research on this population continues to pull participants primarily from northern and western regions and metropolitan areas such as New York City (The Williams Institute, 2016). However, differences in region and community size may create variance in LGBT older adults' perceptions of and experiences in LTC services. LGB individuals living in rural areas and small towns experience certain types of discrimination more frequently than their urban LGB counterparts, including homophobic statements, employment discrimination, and housing discrimination (Swank, Fahs, & Frost, 2013). This history of discrimination may make them more likely to fear discrimination in a LTC setting or impact their perceptions of LTC accessibility. Research has shown that location can also affect the health of transgender individuals: transgender individuals living in the West South Central division of the United States experienced higher levels of anxiety and depression than transgender individuals living elsewhere (Sinnard, Raines, & Budge, 2016). Furthermore, LGBT individuals who live in rural areas may have less ability or willingness to access healthcare resources than their urban counterparts (Barefoot, Smalley, & Warren, 2015). Even if LGBT individuals have the willingness to access resources, regional differences may also cause changes in quality of resources and the type of resources available. In a study investigating agencies serving elders on their services, training, and beliefs about LGBT older adults, rural agencies were less likely to provide targeted services to LGBT older adults, offer staff training about LGBT aging, believe in addressing issues specific to LGBT individuals, and receive requests for assistance from LGBT older adults than urban agencies. Southern agencies were also less likely to provide targeted outreach and services to LGBT individuals, offer or fund LGBT-specific training, express a

necessity for LGBT-specific services, and receive requests for assistance from LGBT individuals than other geographic locations (Knochel, Croghan, Moone, & Quam, 2012). These discrepancies in health, lifetime discriminatory experiences, healthcare utilization, and aging services may create differences in perceptions of and experiences in LTC for LGBT older adults living or growing up in the South.

The current study reports the findings of a survey (n=728) and follow-up phone interviews (n=5) that seek to explore the perceptions and experiences that Southern LGBT older adults have about LTC services and facilities. The quantitative portion of this study looked at the demographics, social support, outness, experienced discrimination, perceptions, and the direct and indirect experiences of LGBT older adults relating to LTC. The supplemental qualitative portion sought to further question LGBT older adults about their perceptions of and experiences in LTC, as well as encourage them to provide recommendations for improvement. Collectively, this study aims to update existing research on LGBT older adults' and LTC after the legalization of marriage equality in the United States. Additionally, this study seeks to address the current lack of research on Southern LGBT older adults' perceptions of and experiences in LTC. By educating LGBT advocates and providers of LTC services about the specific experiences, fears, and recommendations that Southern LGBT elders have about LTC, this study can help to inform LTC policies and regulations. Creating more inclusive LTC services has the potential to improve LGBT older adults' quality of life.

Methods

Participants

Participants were 728 self-identified LGBT older adults who completed a survey on their perceptions of LTC services, and five individuals who were further recruited from the survey sample to participate in phone interviews. To participate in the study, the participants had to: 1) be an older adult, defined as at least 50 years old; 2) live in the Deep South of the United States, which is defined as the following states: NC, SC, GA, AL, MS, LA, FL; 3) be able to speak and read English; and 4) be able to independently provide informed consent. Participants were excluded from participating in the survey if they were: 1) under legal guardianship or 2) unable to provide informed consent. The participants ranged in age from 50 years to 83 years of age ($M=59$). Approximately 66% ($n = 483$) of the participants identified as male, while 31% ($n = 228$) of the participants identified as female. There were additionally three participants who self-identified as transgender men, and fourteen participants who self-identified as transgender women. The participants identified as belonging to the following racial and ethnic categories: White/Caucasian (91%), Black/African American (4.5%), Multiple Ethnicity or Other (3.2%), Latino (3%), Native American/American Indian/Alaska Native (0.8%), and Hawaiian Native/Pacific Islander (0.1%). The participants self-identified as belonging to the following sexual orientations: Gay (63.5%), Lesbian (27.6%), Bisexual (5.8%), Queer (2.1%), Straight (0.7%), and Questioning (0.4%). When asked which state of the Deep South they currently reside in, the participants stated that they live in these states at the following rates: Georgia (20.3%), Florida (18.2%), North Carolina (18.1%), South Carolina (17.7%), Louisiana (11.7%), Alabama

(9%), and Mississippi (5%). Participants were then further asked to classify if they live in areas that are Suburban (47.2%), Urban (32.3%), or Rural (20.6%).

There were initially 876 responses to the survey; however, 148 participants were removed during data cleaning because of incomplete responses or irrelevant responses and were excluded from further data analysis. The data from the remaining 728 participants was further split into two sets based on the gender identity of the participants: cisgender (n=711) and transgender (n=17). Because there were so few respondents who self-identified as transgender in the sample, those respondents were separated into their own dataset in order to better identify how their perceptions of LTC may differ from respondents who were cisgender.

Materials

The survey to determine the perceptions of Southern LGBT older adults on LTC services was online and anonymous, and was deemed exempt by the University of South Carolina IRB. The survey was hosted on SurveyMonkey and was composed of 56 total questions. Demographic information, such as age, race, gender, sexual orientation, relationship and disability status was collected. Further questions were asked regarding their perception of the political climate, social and medical support, as well as their perceptions of LTC. To gauge their perception on LTC, the participants were asked whether they had considered entering LTC, their perceptions of expected discrimination in LTC, and their willingness to utilize these services. Participants were further asked to describe their experiences, whether direct or indirect, with LTC services. These questions were designed by the researchers to be similar to ones utilized in other studies; the full survey can be seen in Appendix A.

Three validated instruments were administered to test for perceived social support, levels of self-reported discrimination, and levels of outness of the participants. These instruments are the Perceived Social Support Scale, the Everyday Discrimination Scale, and the Nebraska Outness Scale. The Perceived Social Support Scale is a 14 item instrument evaluating perceived social support from family/ family of choice (7 questions) and friends (7 questions). Cronbach's $\alpha = .84-.85$ family and $\alpha = .76-.81$ friends; test-retest $r = .94$ family; $r = .88$ friends. Construct and discriminant validity have been established (Rice & Longabaugh, 1996). The Everyday Discrimination Scale is a 9 item instrument measuring self-reported discrimination, on a 6-point likert scale. Follow-up questions assess the ascribed characteristic targeted (i.e. race, language, sexual orientation etc.). (Kershaw, 2016). Scores are summed across the questions with higher numbers indicating more perceived discrimination, cronbach's $\alpha = .88$. The Nebraska Outness Scale is a 10 item scale (composed of two 5 item subscales) answered on an 11pt likert scale. One subscale measures concealment $\alpha = .80$ and the other disclosure $\alpha = .82$ (full scale $\alpha = .89$). The data collected from the survey was organized and analyzed using SPSS.

The phone interviews contained questions meant to further illuminate the participants' perceptions about LTC. Questions were created by the researchers about whether the participants had thought about entering LTC, whether their experience in LTC as an LGBT-identified individual would differ from non-LGBT elders, and whether their experiences would differ in LTC facilities located in the South compared to facilities located elsewhere in the United States. If the participants had previous experience with LTC they were asked to elaborate on those encounters. Additionally, the participants were asked if they had any general or Southern-specific recommendations to prevent discrimination against LGBT individuals in

long-term care settings. The phone interviews were recorded using the phone app TapeACall Pro: Call Recorder. The audio files of the interviews were then transcribed using a transcription service, Verbal Ink. The resulting transcriptions were then analyzed for overall themes by the researchers.

Procedure

Participants were primarily recruited through Facebook advertising of the survey, as well as through LGBT advocacy groups and organizations in each of the Deep South states that further disseminated the survey. Once recruited, participants anonymously filled out an online survey that asked for demographic information, as well as perceptions of long term care, measures of outness, social support, and experiences of discrimination (variables of interest). Informed consent was obtained on the first page of the survey. The survey took participants approximately 20 minutes to complete. After completing the survey, participants were asked if they would be willing to 1) participate in a phone interview; and/or 2) participate in a lottery for a \$50 Visa gift card (5 total for the survey). If participants chose either option, they were asked to list their email for further contact. The participants who agreed to participate in further interviews were contacted via email and asked to schedule a date and time for the phone interview using the Google form constructed by the researchers. To keep the identities of the participants anonymous, the form asked for the email that was provided for further contact, as well as their phone number and pronouns. All information gathered in the survey was confidential, and the participants could only see their own information. The participants were asked to provide this information and schedule one slot from a list of available days and several times. Informed consent for recording the interviews was obtained at the beginning of the

session, and the interviews took approximately 15 minutes to complete. Participants who completed the phone interview were then entered into an additional lottery for another \$50 Visa gift card.

Results

Quantitative Results

Cisgender participants. Seven-hundred and eleven cisgender individuals participated in this study's survey. The average age of these participants was 59 years old ($SD=6.470$), with the youngest respondent(s) being 50 and the oldest respondent being 83 years old. Of these participants, 67.9% identified as male and 32.1% identified as female. Sixty-five percent of the participants identified as gay, 26.6% identified as lesbian, 5.9% identified as bisexual, 2.1% identified as queer, and 0.4% identified as questioning. Additionally, 64.7% of participants

Cisgender Participants' Sexual Orientation

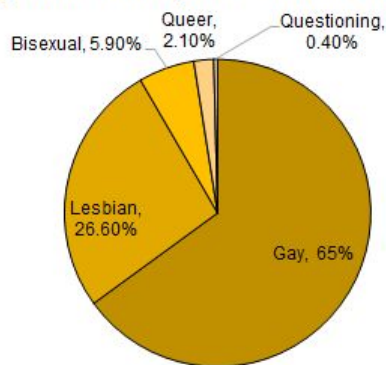


Figure 1. Cisgender participants' sexual orientation

indicated that they were attracted to men, 27.1% indicated that they were attracted to women, and 8.2% indicated that they were attracted to both sexes. Of the individuals who reported their race/ethnicity categories, 91.5% selected white/caucasian, 4.7%

selected black/African American, 3.0% selected multiple ethnicity/other, 0.6% selected Native American/American Indian/Alaska Native, 0.1% selected Hawaiian Native/Pacific Islander, and 0.1% selected that they did not know their racial/ethnicity categories. Of the individuals who reported their highest level of completed education, 33.0% had received a bachelor's degree,

23.9% had received a master's degree, 20.1% had received some college education, 9.3% had received a doctorate degree, 9.2% had received an associate's degree, 3.9% had received a high school diploma, 0.4% had received some high school but no diploma, and 0.1% had never been

to high school. Seven hundred and

six participants reported their

annual household income. Of these

respondents, 28.6% made \$100,000

or greater, 8.5% made

\$50,000-\$59,999, 8.5% made

\$20,000-\$29,999, 8.4% made

\$30,000-\$39,999, 8.4% made

\$40,000-\$49,999, 7.4% made less

than \$14,000, 6.9% made

\$60,000-\$69,999, 6.9% made

\$70,000-\$79,999, 5.7% made

\$14,000-\$19,999, 4.8% made

\$80,000-\$89,999, 4.7% made

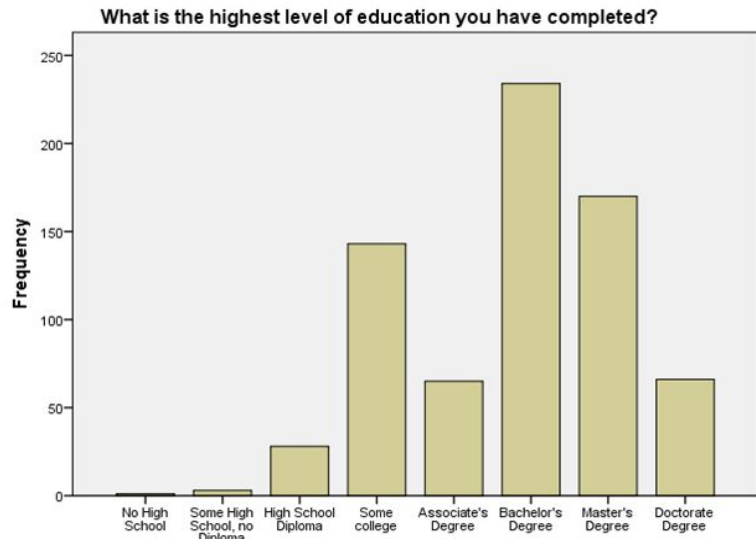
\$90,000-\$99,999, and 1.3%

reported that they did not know

how much they made annually. Of

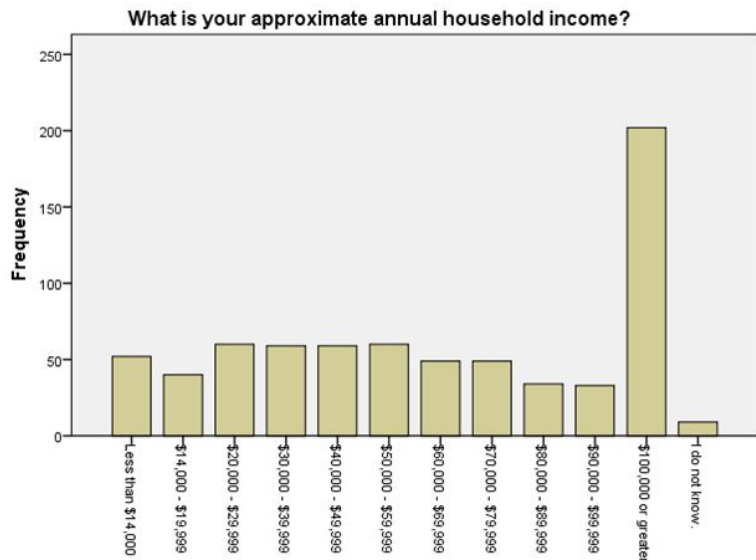
707 cisgender participants, 20.2%

lived in Georgia, 18.5% lived in North Carolina, 18.4% lived in Florida, 17.3% lived in South



What is the highest level of education you have completed?

Figure 2. Cisgender participants' levels of education



What is your approximate annual household income?

Figure 3. Cisgender participants' annual household incomes

Carolina, 12.0% lived in Louisiana, 8.6% lived in Alabama, and 5.0% lived in Mississippi. Of the participants who responded, 47.2% indicated they lived in a suburban area, 32.3% indicated

Cisgender Participants' Location by State

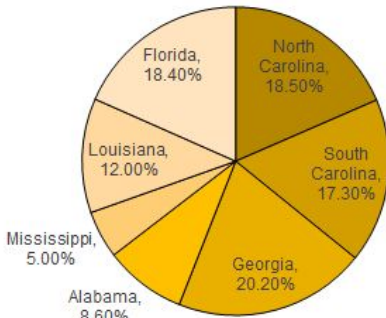


Figure 4. Cisgender participants' location by state

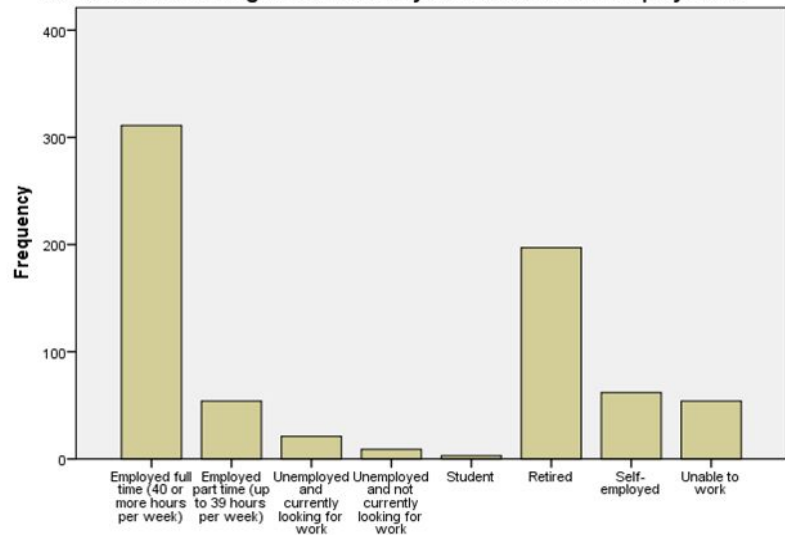
they lived in an urban area, and 20.6% indicated they lived in a rural area. Of the cisgender survey participants, 25.6% lived in one of five major cities in the South, including Miami, Orlando, Tampa, Atlanta, and Charlotte. Thirty-five percent of participants are currently married, 31.2% are single, 23.9% are in long-term partnerships/relationships, 4.6% are widowed, 4.1% are divorced, and 1.1% are separated. Additionally, 43.7% of participants were currently employed full time when this survey was conducted, 27.7% were retired, 8.7% were

self-employed, 7.6% were unable to work, 7.6% were employed part-time, 1.3% were unemployed and not currently looking for work, and 0.4% were students.

Of the respondents who answered whether they agreed or

disagreed with the statement that they had a special person around when they are in need, 544 respondents (76.6%) agreed with this statement to some degree, 43 respondents (6.1%) were

Which of the following best describes your current level of employment?



Which of the following best describes your current level of employment?

Figure 5. Cisgender participants' employment

neutral, and 123 respondents (17.3%) disagreed to some degree. Five hundred and seventy-two participants (80.6%) agreed to some degree with the statement that they had a special person with whom they could share their joys and sorrows, whereas 32 participants (4.5%) were neutral,

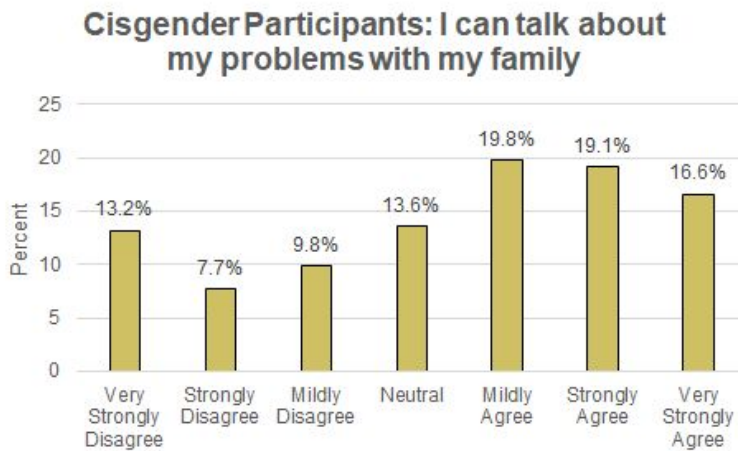


Figure 6. Cisgender participants' reliance on family support systems for problems

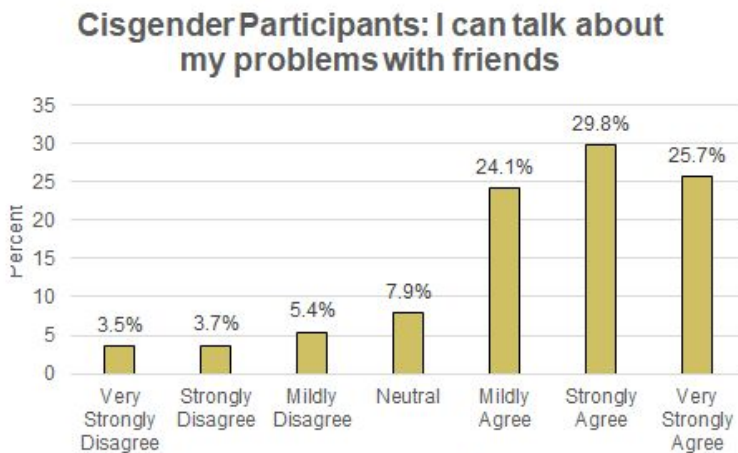


Figure 7. Cisgender participants' reliance on friends for problems

and 107 participants (15.1%) disagreed with this statement to some extent. Of the participants who responded to the statement that they specifically had friends with whom they could share their joys and sorrows, 591

participants (83.5%) agreed to some extent, 42 (5.9%) were neutral, and 75 (10.6%)

disagreed to some extent.

Additionally, 350 participants (49.2%) indicated that they

agreed to some extent with the statement that there is a special person in their life who cares

about their feelings, whereas 39

participants (5.5%) were neutral and 116 participants (16.3%) disagreed with this statement to some extent. Of the participants who responded to the statement that they had a special person

who was a real comfort to them, 559 participants (78.9%) agreed to some extent, 36 participants (5.1%) were neutral, and 113 participants (16%) disagreed to some extent. Of those who responded to the statement that their family really tries to help them, 458 participants (64.7%) agreed with this statement to some extent, 96 (13.6%) were neutral, and 154 (21.7%) disagreed to some extent. Seven hundred and nine participants responded to the statement that they get the emotional help and support that they need from their family, with 402 participants (56.7%) agreeing with this statement to some extent, 98 participants (13.8%) were neutral, and 209 participants (29.5%) disagreed to some extent. Alternatively, of the participants who responded to the statement that their friends really try to help them, 542 participants (76.5%) agreed to some extent, 87 participants (12.2%) were neutral, and 80 participants (11.3%) disagreed to some extent. Five hundred and forty-one participants (76.2%) agreed to some extent with the statement that they could count on their friends when things go wrong, whereas 77 participants (10.8%) were neutral, and 92 participants (13%) disagreed to some extent. Three hundred and ninety-five participants (55.6%) agreed to some extent with the statement that they could talk about their problems with their families, whereas 97 participants (13.6%) were neutral, and 219 participants (30.8%) disagreed to some extent. Alternatively, when responding to the statement that they could talk about their problems with their friends, 564 participants (79.5%) agreed to some extent with this statement, 56 participants (7.9%) were neutral, and 89 participants (12.5%) disagreed to some extent. Additionally, 395 participants (55.8%) of participants agreed with the statement that their family is willing to help them make decisions, 126 participants (17.8%) were neutral, and 187 participants (26.4%) disagreed to some extent.

As for the size of participants' social circles, 29% of participants believed that they could currently rely on 4-6 people for social support, 23.6% believed that they could rely on 1-3 people, and 16.6% believed that they could rely on over 15 people. Twenty-five participants (3.5%) indicated that they did not have anyone that they could rely on for social support.

Participants indicated that they had a smaller amount of people that they could rely upon for social support while aging. Forty percent believed that they could rely upon 1-3 people, 22% believed that they could rely upon 4-6 people, 8.2% believed that they could rely upon more than 15 people, and 5.8% believed that they had no one that they could rely on for social support while aging. Additionally, support network sizes dwindled when considering how many people the participant could rely upon for medical support. Three hundred and seventy respondents (52.1%) indicated that they could rely on 1-3 people for

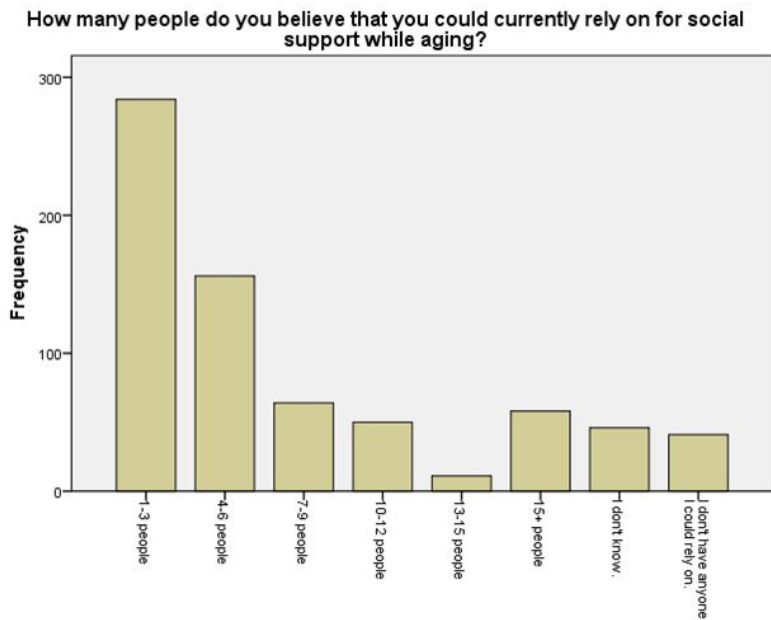


Figure 8. Size of cisgender participants' aging social support systems

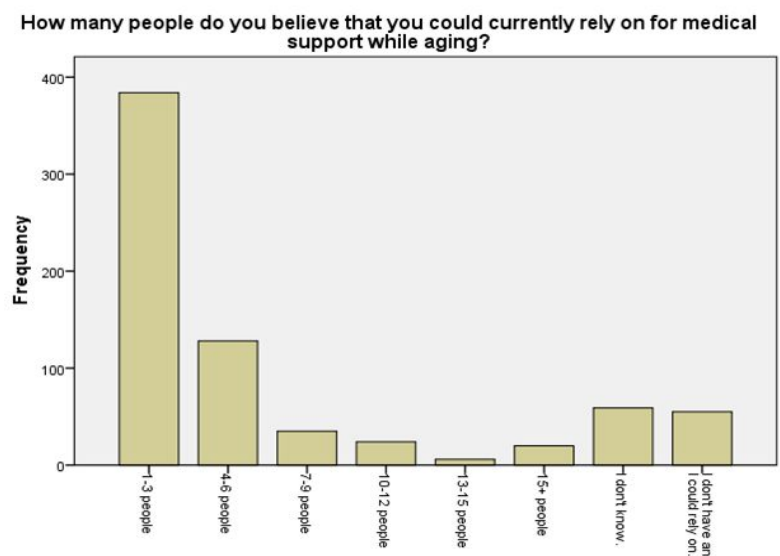


Figure 9. Size of cisgender participants' aging medical support systems

medical support, whereas 23.2% indicated that they could rely on 4-6 people. Only 3.8% of respondents believed that they could rely on over 15 people for medical support, and 6.6% of respondents indicated that they currently did not have anyone that they could rely on for medical support. When considering how many people that they could rely on for medical support while

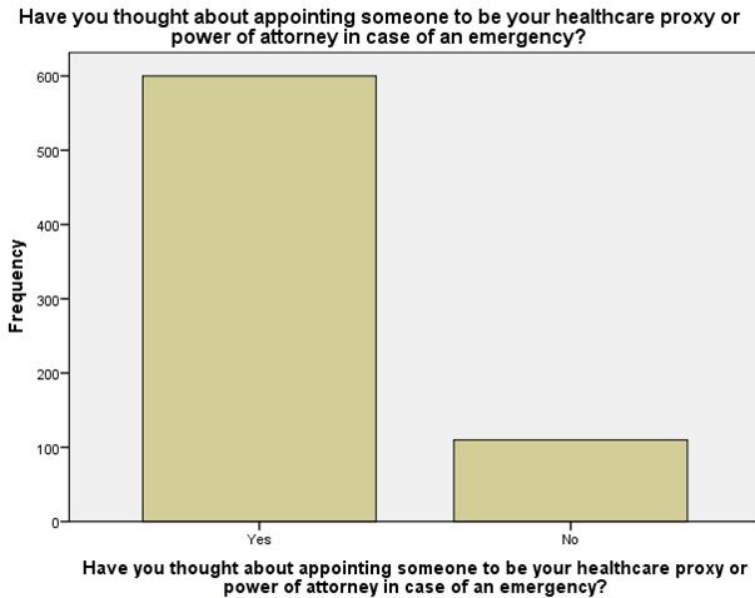


Figure 10. Cisgender participants' consideration of HCPOA

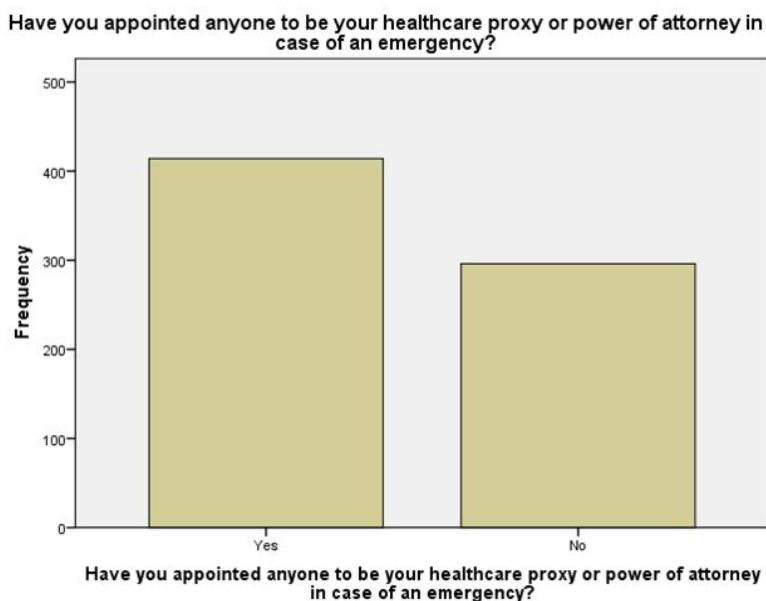


Figure 11. Cisgender participants' amount of HCPOAs

aging, 54% of participants believed that they could only rely on 1-3 people, 18% of participants believed that they could rely on 4-6 people, 2.8% of participants believed that they could rely on over 15 people, and 7.7% believed that they could not rely on anyone for medical

support while aging. Six hundred respondents (84.5%) had thought about appointing someone to be their healthcare proxy or power of attorney, but only 414 respondents (58.3%) had actually appointed someone to serve in this role. Of those who had appointed a person to be

their healthcare proxy or power of attorney, most had appointed a spouse or significant other (62.3%), a family member (21.3%), or friend (12.3%).

When considering daily experiences of discrimination, 51.3% of participants experienced people treating them with less courtesy more than once a year. Fifty percent of participants experienced being treated with less respect than other people more than once a year. Of the individuals who reported whether they had been called names or insulted, 21.5% of participants experienced this discrimination more than once a year. Additionally, of the individuals who reported whether they had been threatened or harassed, 11.5% experienced this type of discrimination more than once a year. The most selected type of discrimination that was experienced more than once a year was people acting as if they are better than the participant (n=369). The most selected type of discrimination overall was people treating the participant with less respect than other people (n=528). Of the individuals who answered “A few times a year” or more frequently to the different types of discrimination listed, 44.2% reported that sexual orientation was the main reason for this discrimination. Other reasons that were frequently selected included age (10.1%), weight (8.2%), and gender (6.7%).

The majority of participants believed that the national (n=538) and state (n=501) political climates towards LGBT individuals is becoming more hostile. However, only 273 participants (38.5%) believed that the local political climate was becoming more hostile towards LGBT individuals. Additionally, 62.3% of respondents believed that discrimination based on sexual orientation and/or gender identity (SOGI) will become more prevalent in the next 5 years, and 54.4% of respondents believed that there will be political changes that decrease their ability to access accepting healthcare services in the next five years. Of all the participants, 75.8% of

respondents believed that the political climate towards LGBT individuals living in the South is worse than in other parts of the United States, and 76.6% of respondents believed that discrimination on the basis of SOGI is more prevalent in the South than other parts of the United States.

Only 42.1% of respondents believed that they would need to use some form of long-term care services in the future and 44.9% were unsure. Only 31.5% of respondents believed that they would have to enter into a long-term care facility in the future and 50.8% were unsure if they would have to do so. Additionally, the majority of respondents (n=663) had not considered using long-term care services in the past year. Despite the participants' lack of consideration of long-term care services, 21.3% of respondents rated themselves as very knowledgeable of LTC services, 32.7% of respondents rated themselves as knowledgeable, and 36.6% of respondents rated themselves as slightly knowledgeable. Only 9.4% of respondents indicated that they were not knowledgeable of LTC services.

When reporting perceptions of discrimination against individuals because of actual or perceived SOGI in LTC facilities, 317 participants believed that individuals may be refused

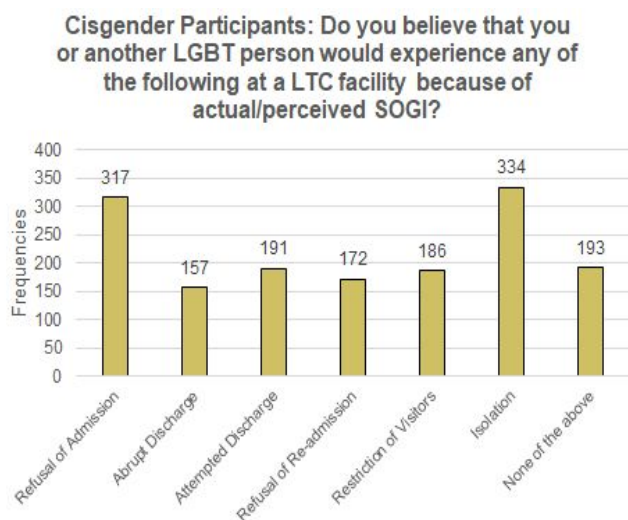


Figure 12. Cisgender participants' perceptions of discrimination

admission, 157 participants believed that individuals may face abrupt discharge, 191 participants believed that individuals may face attempted discharge, 172 participants believed that individuals may experience refusal of admission, 186 participants believed that individuals may experience a

restriction of visitors, and 334 participants believed that individuals may experience isolation. Additionally, 295 respondents believed that faculty or staff of a LTC would refuse a person basic services based on their actual or perceived SOGI, 420 respondents believed that faculty or staff might verbally harass or ostracize a person, 265 respondents believed that faculty or staff might physically abuse a person, 388 respondents believed that faculty or staff might refuse to refer to a transgender resident by their preferred name or pronouns, and 313 respondents believed that faculty or staff would refuse to let the spouse, partner, or person with the health care directives for a LGBT resident make decisions about the resident's health. Four hundred and forty-six respondents (63%) believed that a LGBT person might experience verbal

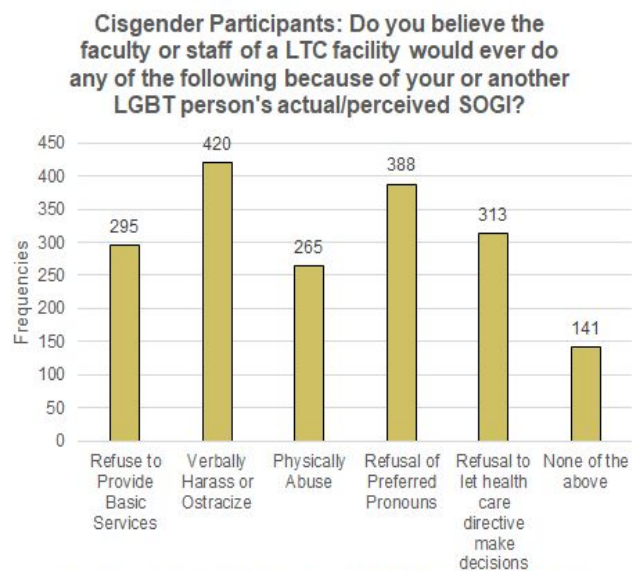


Figure 13. Cisgender participants' perceptions of faculty discrimination

harassment or abuse by residents of a long-term care facility because of their actual or perceived SOGI. Two hundred and eighty-one respondents (39.6%) believed that a LGBT person might be denied medical treatment from staff because of actual or perceived SOGI. Four hundred and seventy (66.3%) of respondents believed that LTC facilities in the South would be more likely to discriminate based on SOGI than those in other parts of the United States.

Cisgender participants indicated different levels of willingness to enter certain types of LTC services and facilities. Five hundred and ninety-seven respondents (85.6%) indicated that they would be willing to some degree to utilize home care services, whereas 515 respondents

(73.8%) were willing to some degree to utilize community services and 490 respondents (70.1%) were willing to some degree to utilize supportive housing programs. Three hundred and eighty-five respondents (55.1%) were willing to some degree to utilize continuing care retirement facilities and 413 respondents (59.2%) were willing to some degree to utilize assisted care facilities. Participants were least willing to utilize nursing home services, with only 236 respondents (33.8%) indicating some degree of willingness. A majority of respondents (n=582) indicated that they would be more willing to utilize LTC services provided by LGBT people than those provided by non-LGBT people and 599 respondents (85.8%) indicated that they would be more willing to enter LTC facilities specifically for LGBT people. However, only 46.6% of respondents indicated that they would be more willing to enter LTC facilities for their specific SOGI than a LTC facility for LGBT people in general.

The cisgender participants also had varying degrees of comfort with disclosing their SOGI status to different individuals in LTC settings. When considering disclosing their SOGI to unknown providers of LTC services, 51.2% of participants were comfortable to some degree with disclosing this information, whereas 35.8% of participants were fearful to some degree. However, only 42.2% of participants were comfortable to some degree with disclosing this information to other individuals working in LTC facilities. Forty-two percent of participants were comfortable to some degree with disclosing this information to residents of LTC facilities.

Only 82 respondents (11.8%) had personally used LTC services or known another LGBT person who used LTC services. However, of those who did personally utilize LTC services or knew another LGBT person who used LTC services, 50.6% knew a person who concealed their SOGI in a LTC setting out of fear of discrimination.

Transgender participants. After data cleaning, this survey only had seventeen respondents who identified as transgender. Because of this small sample size, the data from the transgender participants is not statistically significant for analysis. However, of these participants, three identified as trans men and fourteen identified as trans women. Twelve identified as lesbian and five identified as straight. Only one transgender participant was attracted to men, whereas twelve participants were attracted to women and four were attracted to both men and women. Thirteen participants were white/Caucasian, two Native American/American Indian/Alaska Native, and two were of multiple ethnicities. Eight (47%) had completed a bachelor's degree, four (24%) had completed some college, three (18%) had

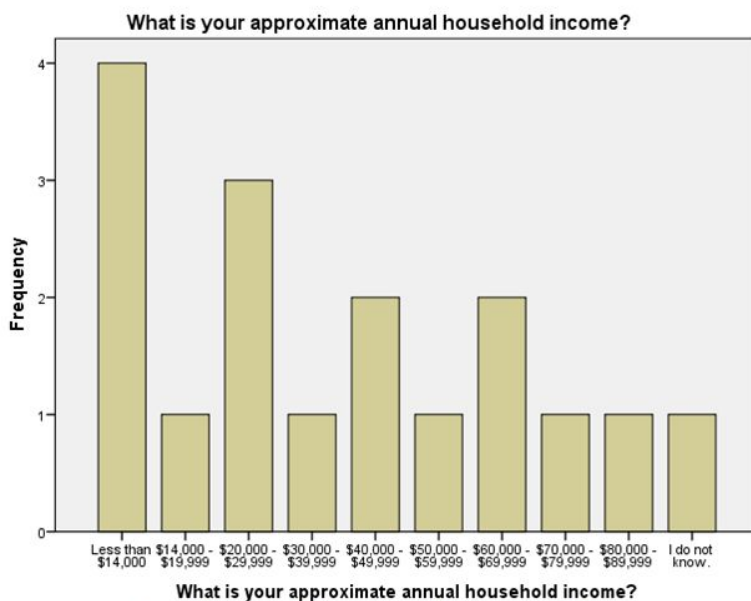


Figure 14. Transgender participants' annual household income

completed an associate's degree, and two (12%) had completed a master's degree as their highest levels of education. The most selected wealth category (n=4) made less than \$14,000 annually as a household and the highest reported annual household income was \$80,000-\$89,999.

Additionally, six of the transgender participants were currently living in South Carolina, with four living in Georgia, four living in Alabama, two living in Florida, and one living in Mississippi. Nine of these participants indicated that the area in which they lived was suburban, six indicated that they lived in rural areas, and only two indicated that they lived in urban areas.

Only two transgender participants indicated that they lived in major metropolitan areas in the South: Orlando and Atlanta. Seven transgender participants were single, four were married, two were in long-term partnerships/relationships, two were widowed, and two were divorced. Six were employed full time, three were retired, three were unable to work, two were employed part time, two were self-employed, and one was unemployed and currently looking for work.

When responding to the statement that they had a special person around when they were in need, nine transgender participants agreed to some extent with this statement, three were neutral, and eight disagreed to some extent. Eleven participants agreed to some extent with the statement that they had a special person with whom they can share their joys and sorrows, whereas two were neutral and four disagreed to some extent. Only three disagreed to some extent with the statement that they

had a special person who is a real source of comfort to them, whereas twelve agreed to some extent. Eleven agreed to some extent with the statement that they had a special person in their life who cared about their feelings.

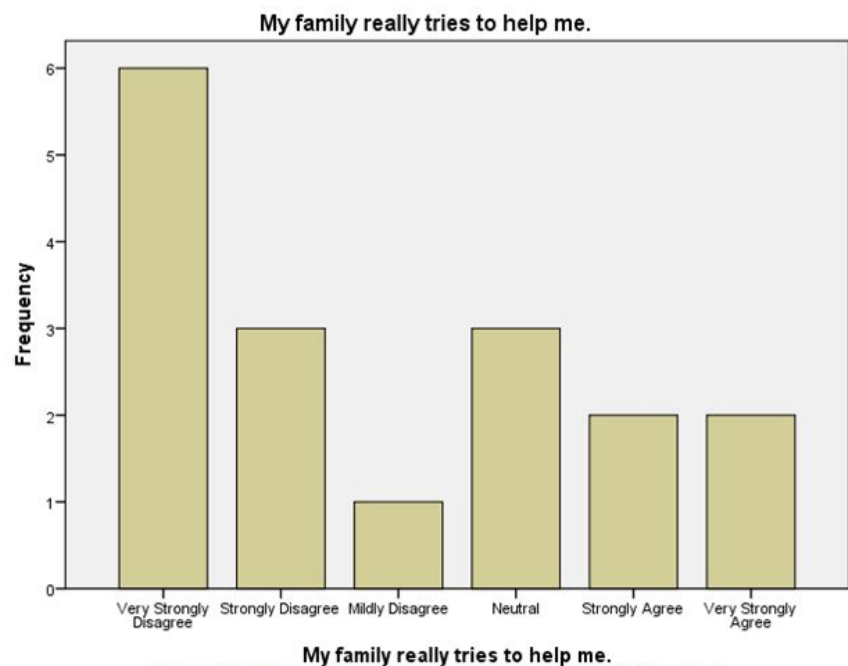
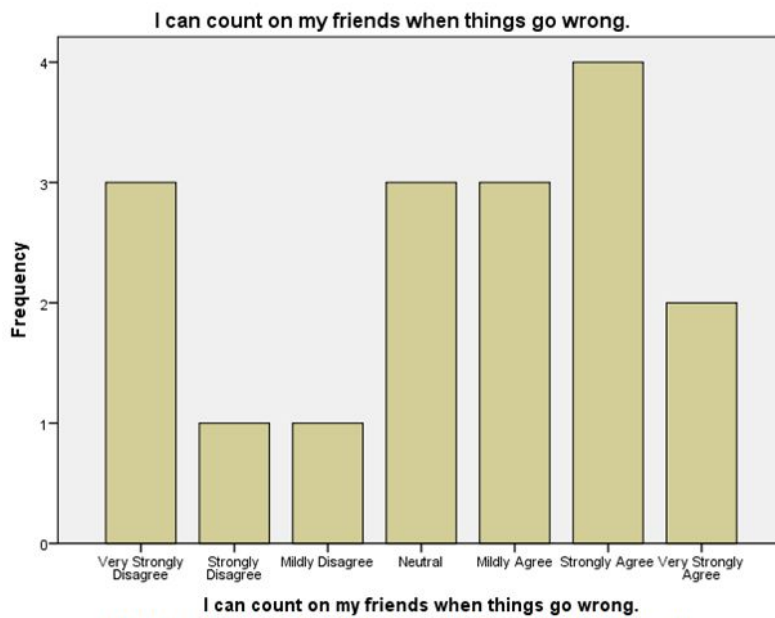


Figure 15. Transgender participants' belief in familial support

However, ten transgender participants disagreed to some extent with the statement that their families were really trying to help them, and only four agreed to some extent with this statement.

Additionally, twelve participants disagreed to some extent and three agreed to some extent with the statement that they could get the emotional help and support that they needed from their family. Ten participants disagreed and four participants agreed to some extent with the statement that they could talk about their problems with their family. Eleven participants indicated that



they disagreed to some extent with the statement that their family is willing to help them make decisions. Transgender participants' ability to rely upon friends for support was also lower than the cisgender participant pool. Only nine agreed with the statement that

their friends really try to help them and with the statement that they could count on their friends when things go wrong. Nine also indicated that they agreed with the statement that they have friends with whom they can share their joys and sorrows, and eight agreed to some extent with the statement that they can talk about their problems with their friends.

The transgender participants also had higher levels of everyday discrimination. Fifteen participants indicated that they were treated with less courtesy than other people are more than once a year, with six participants selecting more than once a week. Sixteen participants also indicated that they were treated with less respect than other people are more than once a year, with seven indicating that this type of discrimination happens to them more than once a week.

Thirteen participants indicated that people act as if they are better than the respondent more than once a year. Thirteen participants also indicated that they are called names or insulted more than once a year, with only one selecting that they experience this discrimination more than once a week. Thirteen also indicated that they are threatened or harassed more than once a year, with five indicating that they experience this type of discrimination a few times a month. When asked the main reason for these experiences of discrimination that occur more than “A few times a year,” five participants selected gender and seven selected other reasons.

Only three transgender participants indicated that they believed they would have to use LTC services in the future, with four indicating that they believed they would not have to do so and ten indicating that they were unsure. This uncertainty increased when asked if they believed that they would have to enter into a LTC facility in the future, with two reporting that they believed they would, three reporting that they believed they would not have to do so, and twelve reporting that they did not know. Only one respondent had considered using LTC services in the past year. Nine transgender participants indicated that they felt knowledgeable of LTC services, seven participants indicated that they felt slightly knowledgeable, and one indicated that they felt not knowledgeable.

When indicating what types of discrimination that they believed an LGBT person would experience at a LTC facility because of actual or perceived SOGI, thirteen participants believed individuals may be refused admission, seven believed that individuals may be abruptly discharged, six believed that individuals may experience attempted discharge, six believed that individuals may experience refusal of readmission, five believed that individuals may experience a restriction of visitors, and eleven believed that individuals may experience isolation. Ten

participants believed that the faculty or staff of a LTC facility might refuse to provide basic services to a person based on their actual or perceived SOGI, ten also believed that an individual may experience verbal harassment from faculty or staff, seven believed that an individual may experience physical abuse from faculty or staff, thirteen believed that an individual may experience faculty or staff refusal to use a preferred name or pronoun, and four believed that an individual may experience faculty or staff refusal to let a spouse, partner, or person with the medical power of attorney or health care directive make decisions for an LGBT resident. Twelve believed that a person might experience verbal harassment or abuse by residents of an LTC facility because of SOGI and six participants believed that the staff of a LTC facility would deny a person medical treatment because of SOGI. Ten participants believed that LTC

Transgender Participants: Do you believe that you or another LGBT person would experience any of the following at a LTC facility because of actual/perceived SOGI?

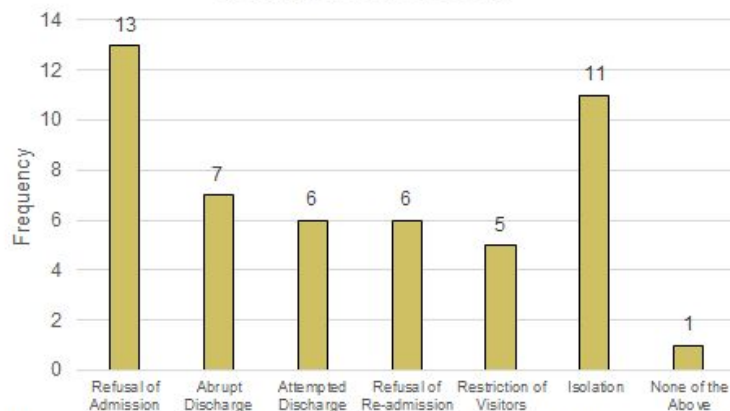


Figure 17. Transgender participants' perceptions of discrimination

Transgender Participants: Do you believe the faculty or staff of a LTC facility would ever do any of the following because of your or another LGBT person's actual/perceived SOGI?

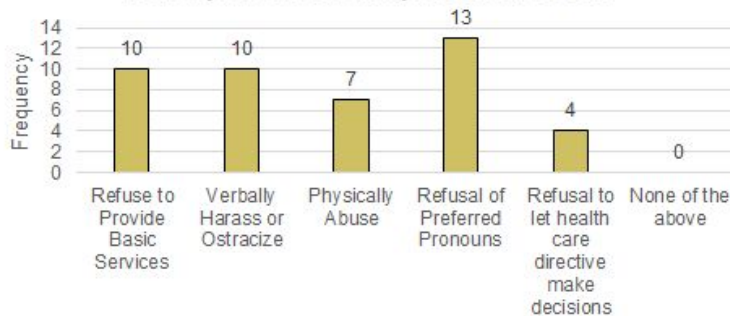


Figure 18. Transgender participants' perceptions of discrimination from staff

facilities in the South would be more likely to discriminate based on SOGI than other parts of the United States.

When reporting their willingness to utilize certain types of LTC services, ten participants indicated some degree of willingness to use home care services, eleven indicated some degree of willingness to use community services, and nine indicated some degree of willingness to use supportive housing programs. Only six participants indicated that they would be willing to some degree to use continuing care retirement facilities, six indicated that they would be willing to some degree to use assisted care facilities, and four indicated that they would be willing to some degree to use nursing homes. Fifteen respondents (88%) indicated that they would be more willing to use LTC services provided by LGBT people than those provided by non-LGBT people and thirteen (76%) indicated that they would be more willing to use LTC facilities specifically for LGBT people. Nine respondents (53%) indicated that they would be more willing to enter LTC facilities for their specific SOGI than a LTC facility for LGBT people in general.

Qualitative Results

Five phone interviews were conducted with respondents who expressed interest from the survey. These respondents were asked to answer a total of five questions about their perceptions of long-term care. When asked if they personally thought about what it would be like to enter LTC as an LGBT person, the majority of them answered in the affirmative, stating their aging and health issues as reasons for this. A common theme additionally arose that they did not feel that they have positive family support for their sexual orientation or gender identity - "I can't count on my family. I don't want to count on my family, maybe."

When asked if they believed that their experience as an LGBT individual would differ

from non-LGBT elders, the general opinion was that of agreement. Some participants had prior experience working in the field of LTC and witnessed discrimination against residents there. One individual stated that “the way the staff treated them was so wrong. They were highly discriminated upon, things that were said to them. It wasn’t healthy, it wasn’t respectable.” Others felt that they would be forced to reenter the closet, saying that “I don’t feel like I could live the life that I have chosen. I mean to be out, chosen to be out, and I [would] have to live in a closet because I’m in a nursing home.”

Participants were then asked if their experiences as an LGBT individual would differ in LTC facilities in the South versus elsewhere in the country. There were mixed responses to this question. For example, one individual expressed the concern that the “staff might treat me differently, especially here in the South.” However, another participant expressed the viewpoint that the anti-LGBT discrimination they’ve experienced is “almost equal” in various locations around the country. Another individual stated that they feel discrimination is more subtle in the North but is more overt in the South, talking about South Carolina specifically. A viewpoint was also expressed that the Northeast in particular is more accepting of LGBT individuals than the South is.

Participants also had mixed responses when asked about their experiences in interacting with LTC. Some had negative experiences or witnessed others have negative experiences with long-term care facilities, stating that those individuals experienced discrimination from the staff as well as the residents of the facility. One individual said that their friends had positive experiences with in-home services, explaining “that person has a little bit more power as to who steps through their door, as opposed to being in a facility.” Another participant stated that they

had a positive experience with their mother in LTC, and “became friends with the staff.”

The final question in the phone interview was whether the participants had any general or Southern-specific recommendations to prevent discrimination against LGBT individuals in LTC settings. One recommendation from a participant was to create a facility for LGBT individuals that “go[es] from retirement, assisted living to nursing homes”; this is commonly referred to as as a Continuing Care Retirement Community (CCRC). The participants in the phone interviews generally agreed that facilities needed to be created specifically for the LGBT community, with one participant stating that “it’d be nice to be with somebody that I could be myself with, and not hide who I am.” Other participants expressed the need for policy changes within existing LTC facilities, stating that they think more sensitivity and diversity training for LTC staff and care providers is needed. One participant stated that they would recommend an increased number of LGBT care providers within LTC facilities as well.

Discussion

This study primarily consisted of well-educated white gay men with relatively low levels of everyday discrimination and high levels of outness. Despite this lack of everyday discriminatory experiences, a large portion of the sample still believed that national and state political climates towards LGBT people were becoming more hostile. However, fewer believed that their local communities were becoming more hostile towards LGBT-identified people. Due to their high levels of education, this sample may be more aware of anti-LGBT legislation being proposed, thereby causing them to perceive the national and state political climate as more unaccepting. However, since this sample also has low levels of everyday discrimination and high levels of outness, they may not perceive their local climates as hostile because they are not currently experiencing increased levels of discrimination. A majority of participants also believed that political changes over the next five years will affect their ability to access inclusive healthcare services. This sample's general negative perceptions of the political climate surrounding LGBT individuals and LGBT identities may cause them to perceive LTC services as less accepting as well.

When responding to the statements in the Perceived Social Support Scale, more participants indicated that they could trust their friends than their families for certain types of social support, such as helping them to solve problems. Transgender participants also had less trust in their social support systems, including both families and friends, than their cisgender counterparts. These results are consistent with existing literature, which suggests that LGBT individuals may be more likely to rely upon families of choice for support. However, since these families of choice are often not legally recognized, it is important that LGBT individuals who

wish to rely upon members of their families of choice for medical support have these individuals legally recognized through a medical directive. However, among our sample, only 58.3% of cisgender respondents and 29.4% of transgender respondents had appointed someone to be their healthcare proxy or power of attorney in case of an emergency.

A large portion of participants in this study also believed that discrimination existed in LTC facilities, and that this discrimination could be perpetuated by residents, providers, and staff. The types of discrimination that most participants believed would be most likely to exist in LTC settings included isolation, refusal of admission, verbal harassment, and refusal to use preferred names and pronouns. Despite perceiving LTC services as potentially discriminatory, the participants in this study were relatively willing to use community services, home-based services, and supportive housing programs. However, they were very unwilling to use nursing homes for LTC services. Additionally, relative to LGBT discrimination a majority of the participants had negative perceptions of the South and the LTC services provided in the South, stating that the South and its LTC services were more discriminatory than in other parts of the United States. To improve LTC services, participants recommended creating more LGBT-specific LTC options, hiring more LGBT providers, and implementing diversity trainings for providers and staff members.

Limitations

There are several limitations to this study. The primary limitation is related to sampling. Although our recruitment efforts sampled from all states in the Deep South, we obtained few participants from Mississippi and Alabama than from the other states. More significantly, by collecting responses exclusively online, the participant pool skewed younger and less likely to

have experiences with LTC, as older demographics and specifically those in LTC facilities are less present online and less comfortable with online surveys. Dissemination of the survey was further limited by the low response rate of the LGBTQ organizations who were approached to share the survey. Although more than 70 organizations were contacted, fewer than ten responded. This resulted in the majority of recruitment to be accomplished through Facebook advertising, which further narrowed the participant pool to Southern LGBT people over 50 years of age who are comfortable with an online survey and active on Facebook.

With the online format already skewing the sample younger and less likely to have LTC experience, Facebook advertising presented further complications in recruiting people of color, transgender people, and women. In the past, Facebook's Ads allowed users to specifically target by race through the demographic tool labeled "Ethnic Affinity," which classifies users' races based on their behavior on facebook, rather than on users self-reported race. Originally this feature could be used as both an inclusion and exclusion criteria. However, due to misuse of the exclusion feature for the purposes of credit, employment, and housing discrimination, Facebook disabled then changed the function (Angwin, 2017). After the changes, "ethnic affinity" was relabeled "multicultural affinity" and moved from the demographic tools to the behavior tools, to reflect that it is more indicative of a users racially/culturally coded behavior on the platform rather than their actual race or ethnicity. While there is no public statement confirming that the name change of "ethnic affinity" was accompanied by a revision of the algorithm behind the tool, there is reason to believe that the multicultural affinity tool is not as accurate in identifying user race. For instance, all of the researchers, who are white women, are listed as having an "African American Multicultural Affinity" in their Facebook Ad details. Even after disabling the

general recruitment advertisement, which had no racial specifications, and shifting all advertising funds to the advertisement targeting those with multicultural affinities, there was no change in the vast majority of new participants, who were still white. Additionally, even if Facebook allowed exclusion by multicultural affinity, because Facebook does not have a “White Affinity” we would not be able to exclude from the advertisement targeting those who Facebook sees as white.

Facebook poses further complications to recruiting transgender people. Despite including as many trans related interest terms as possible, the survey did not reach many transgender participants. Although Facebook allows users to select from over 50 gender identity labels (Dewey, 2014), it does not allow advertising targeting based on them. In addition, recruiting women (cisgender and transgender), was more difficult than recruiting men. Despite the ad being shown to more women, and women’s ad views and clicks costing twice as much as men’s, there were markedly fewer female participants. This may be due to “ad blindness,” a phenomenon which makes a person less aware of and susceptible to advertising due to constant exposure. Generally, ad blindness is considered to be more prominent among women and young people.

In addition to the limits created by Facebook’s advertising tools, the data may also be limited by participants’ interpretations of certain terms, such as “long-term care” and “long-term care facilities.” Although, the survey provided a definition of LTC that included home care provided by friends and family, participants may not have considered those as LTC services. For example, only 42.1% believed that they would need long-term care services in the future (Question 37; Appendix A). This low rate indicates that participants may not have been including being cared for by friends and family as a form of LTC. Therefore, the results may not

reflect application of a complete, consistent understanding LTC. The results also cannot be a directly compared to previous surveys, as there is no established, valid instrument for examining perceptions of or experiences with long term care. The survey did, however, use questions or questions similar to previous surveys. Finally, the processing of the data is not yet complete, so the results, as presented, are not complete or fully contextualized within the rest of the data.

The limitations of the qualitative data are mostly due to the small sample size. Only five participants were interviewed, due to scheduling issues and the imminent senior thesis deadline. Initially, the qualitative data was to be gathered through three focus groups in South Carolina. Despite 370 participants from a variety of states indicating willingness to participate in a focus group, focus groups were not logistically feasible because even the South Carolinian participants were too disperse. Because of this, following an IRB amendment, qualitative data was collected via individual phone interviews. More than 50 participants were contacted to ask for phone interviews, but only seven responded, with just five actually scheduling and completing an interview.

Conclusion

Summary

In this study, the perceptions and experiences that Southern LGBT older adults have regarding long-term care facilities and services were measured via an online survey (n=728) and follow-up phone interviews (n=5). The resulting data analysis found that this population has many negative perceptions of LTC, especially with facilities or services located in the South. They also believe that as LGBT individuals, they would be discriminated against within LTC services on the basis of their sexual orientation and/or gender identity. While a lack of research still remains on the topic of LGBT older adults and long-term care, this study helped to illuminate their perceptions and make them known. Those perceptions can help inform LTC facilities and care providers about the specific fears and recommendations that Southern LGBT older adults have about long-term care. The data gathered in this study can additionally be utilized to inform LTC policies and regulations in order to create more welcoming and LGBT-inclusive spaces in long-term care, which would improve LGBT older adults' quality of life overall.

Implications

The result of this study led the researchers to question the prospective well being of the LGBT community as its members age and enter long-term care. If they are doomed to experience fear, discrimination, and struggle in their "golden years," can the community really be considered thriving? Additionally, the study raises issues of financial, legal, and medical planning for aging LGBT people. If participants do not think they will need LTC services, they are probably not financially planning for it or educating themselves on their rights within it. In

addition to future research, this study warrants the attention of advocacy organizations who are committed to protecting both elderly and LGBT people.

The results of this research leave several clear avenues for follow up research. Future work should explore the potential that negative perceptions of LTC services and facilities may lead to negative health outcomes, such as reticence to utilize care or delaying seeking care. Additionally, subsequent studies should focus on including people of color and trans people, who were underrepresented in this sample. There should also be an emphasis on determining the actual experiences of LGBT people in LTC; this will help determine whether or not the perceptions reflect the reality.

Next Steps

Moving forward, the researchers will write and submit two manuscripts based on this research. One will focus on participants perceptions of and experiences of LTC; the other will examine rural, suburban, and urban differences in the data. The manuscripts will be submitted to the *Journal of Applied Gerontology* and the *Journal of Gerontological Social Work*. Additionally, the researchers will formulate a policy brief to disseminate to advocacy organizations. They will also seek to disseminate the research to healthcare providers, LTC providers, researchers, and LGBTQ organizations. At this writing we have presented this data at *Discover USC*, and the *Southern Gerontological Society* conferences.

Timeline

Date	Journal of Applied Gerontology	Journal of Gerontological Social Work
7/1/18	Draft 1	
8/1/18	Revision	Draft 1
9/1/18	Submission	Revision
10/1/18		Submission

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Appendices

Appendix A

Survey Questions

About the Study

We are looking for adults who are at least 50 years old and identify as LGBT. This one-time survey should take 20 minutes to complete.

To participate you need to be:

1. At least 50 years old
2. Self-identify as lesbian, gay, bisexual or transgender
3. Currently residing in North Carolina, South Carolina, Georgia, Alabama, Mississippi, Louisiana or Florida
4. Able to read and write English

Still interested? Click "Next" to continue.

Consent Letter

Hello,

We are undergraduate students at the University of South Carolina Honors College. We are conducting a research survey for our Senior Thesis and would like to invite you to participate.

We are studying LGBT elder adults' perceptions of long term care. If you decide to participate, you will be asked to complete a survey about your experiences with and/or perceptions of long term care. In particular, you will be asked questions about perceptions of discrimination, amount of social support, level of outness, knowledge of long-term care, and willingness to enter long-term care. You may feel uncomfortable answering some of the questions, but you are not required to answer any questions that you do not wish to.

The survey, which will be hosted on Survey Monkey, will take about 20 to 30 minutes. If you opt in at the end of the survey, you will be entered to win a \$50 Visa gift card. You will only be contacted after the survey if you elect to participate in the focus group or win the raffle. Survey results will be anonymous, and will only be analyzed by members of the research team. Study information will be kept in a secure location at the University of South Carolina. The results of the study may be published or presented at professional meetings, but your identity will not be revealed. Taking part in the survey is your decision. You may quit the survey at any time or decide not to answer any question you are not comfortable answering.

We will be happy to answer any questions you have about the study. You may contact us at lgbteldersht@gmail.com or our faculty advisor, Dr. Laura Hein, if you have study related questions or problems. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at 803-777-7095.

Thank you for your consideration. If you would like to participate, please click "NEXT" at bottom of the screen to begin the survey.

With kind regards,
Lexus Dickson
Alexis Nanna
Megan Taylor

* 1. How old are you, in years?

2. Do you identify as:

- ☐ Male
- ☐ Female
- ☐ Trans man
- ☐ Trans woman
- ☐ Gender non-conforming
- ☐ Other (please specify)

3. What is your sexual orientation?

- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Straight
- ☐ Queer
- ☐ Questioning
- ☐ Other (please specify)

4. Are you attracted to:

- ☐ Men
- ☐ Women
- ☐ Both

5. Which race/ethnicity best describes you? (Please choose only one.)

- ☐ Native American / American Indian / Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hawaiian Native / Pacific Islander
- ☐ White / Caucasian
- ☐ I do not know.
- ☐ Multiple ethnicity / Other (please specify)

6. Do you consider yourself to be:

- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino
- ☐ I do not know.

7. What is the highest level of education you have completed?

- ☐ No High School
- ☐ Some High School, no Diploma
- ☐ High School Diploma
- ☐ Some college
- ☐ Associate's Degree
- ☐ Bachelor's Degree
- ☐ Master's Degree
- ☐ Doctorate Degree

8. Do you have a diagnosed disability?

- ☐ Yes
- ☐ No

9. If yes, check all that apply:

- ☐ A sensory impairment (vision or hearing)
- ☐ A mobility impairment
- ☐ A learning disability (e.g., ADHD, dyslexia)
- ☐ A mental health disorder
- ☐ Other (please specify)

10. What is your approximate annual household income?

- ☐ Less than \$14,000
- ☐ \$14,000 - \$19,999
- ☐ \$20,000 - \$29,999
- ☐ \$30,000 - \$39,999
- ☐ \$40,000 - \$49,999
- ☐ \$50,000 - \$59,999
- ☐ \$60,000 - \$69,999
- ☐ \$70,000 - \$79,999
- ☐ \$80,000 - \$89,999
- ☐ \$90,000 - \$99,999
- ☐ \$100,000 or greater
- ☐ I do not know.

11. Please select the state in which you currently reside.

12. Do you live in an area that is:

- ☐ Suburban
- ☐ Rural
- ☐ Urban

13. Please indicate if you live in any of the following cities.

14. How long have you lived in your current zip code?

- ☐ Less than a year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ More than 15 years

15. Prior to this location, where did you live the longest? (Please enter country, state, and city.)

16. Which of the following best describes your current relationship status?

- ☐ Single
- ☐ Long-term partnership/relationship
- ☐ Married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated

17. Which of the following best describes your current level of employment?

- ☐ Employed full time (40 or more hours per week)
- ☐ Employed part time (up to 39 hours per week)
- ☐ Unemployed and currently looking for work
- ☐ Unemployed and not currently looking for work
- ☐ Student
- ☐ Retired
- ☐ Self-employed
- ☐ Unable to work

18. What percent of the people in this group do you think are aware of your sexual orientation (meaning they are aware of whether you consider yourself straight, gay, etc)?

	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Members of your immediate family (e.g., parents and siblings)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Members of your extended family (e.g., aunts, uncles, grandparents, cousins)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People you socialize with (e.g., friends and acquaintances)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People at your work/school (e.g., coworkers, supervisors, instructors, students)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strangers (e.g., someone you have a casual conversation with in a line at the store)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. How often do you avoid talking about topics related to or otherwise indicating your sexual orientation (e.g., not talking about your significant other, changing your mannerisms) when interacting with members of these groups?

	Never					Half of the Time					Always
Members of your immediate family (e.g., parents and siblings)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Members of your extended family (e.g., aunts, uncles, grandparents, cousins)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People you socialize with (e.g., friends and acquaintances)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People at your work/school (e.g., coworkers, supervisors, instructors, students)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strangers (e.g., someone you have a casual conversation with in line at the store)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
There is a special person who is around when I am in need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a special person with whom I can share joys and sorrows.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family really tries to help me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get the emotional help & support I need from my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a special person who is a real source of comfort to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My friends really try to help me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can count on my friends when things go wrong.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can talk about my problems with my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have friends with whom I can share my joys and sorrows.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a special person in my life who cares about my feelings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family is willing to help me make decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can talk about my problems with friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. In your day-to-day life, how often do any of the following things happen to you?

	Never	Less than once a year	A few times a year	A few times a month	At least once a week	Almost everyday
You are treated with less courtesy than other people are.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are treated with less respect than other people are.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You receive poorer service than other people at restaurants or stores.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People act as if they think you are not smart.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People act as if they are afraid of you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People act as if they think you are dishonest.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People act as if they're better than you are.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are called names or insulted.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are threatened or harassed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. If you answered "A few times a year" or more frequently to at least one option in the question above, what do you think is the main reason for these experiences?

- ☐ Your Ancestry or National Origins
- ☐ Your Gender
- ☐ Your Race
- ☐ Your Age
- ☐ Your Religion
- ☐ Your Height
- ☐ Your Weight
- ☐ Some other Aspect of Your Physical Appearance
- ☐ Your Sexual Orientation
- ☐ Your Education or Income Level
- ☐ A Physical Disability
- ☐ Other (please specify)

23. Do you believe that the national political climate towards LGBT individuals is becoming more hostile?

- ☐ Yes
- ☐ No
- ☐ I don't know.

24. Do you believe that your state political climate towards LGBT individuals is becoming more hostile?

- ☐ Yes
- ☐ No
- ☐ I don't know.

25. Do you believe that your local political climate towards LGBT individuals is becoming more hostile?

- ☐ Yes
- ☐ No
- ☐ I don't know.

26. Do you believe that discrimination based on sexual orientation and/or gender identity will become more prevalent in the next 5 years?

- ☐ Yes
- ☐ No
- ☐ I don't know.

27. Do you believe that there will be political changes that will decrease your ability to access accepting healthcare services over the next 5 years?

- ☐ Yes
- ☐ No
- ☐ I don't know.

28. Do you believe that the political climate towards LGBT individuals living in the South is worse than for those living in other parts of the United States?

- ☐ Yes
- ☐ No
- ☐ I don't know.

29. Do you believe that discrimination on the basis of sexual orientation and/or gender identity is more prevalent in the South than in other parts of the United States?

- ☐ Yes
- ☐ No
- ☐ I don't know.

30. How many people do you believe that you could currently rely on for social support?

- ☐ 1-3 people
- ☐ 4-6 people
- ☐ 7-9 people
- ☐ 10-12 people
- ☐ 13-15 people
- ☐ 15+ people
- ☐ I don't know.
- ☐ I don't have anyone I could rely on.

31. How many people do you believe that you could currently rely on for medical support?

- ☐ 1-3 people
- ☐ 4-6 people
- ☐ 7-9 people
- ☐ 10-12 people
- ☐ 13-15 people
- ☐ 15+ people
- ☐ I don't know.
- ☐ I don't have anyone I could rely on.

32. How many people do you believe that you could currently rely on for social support while aging?

- ☐ 1-3 people
- ☐ 4-6 people
- ☐ 7-9 people
- ☐ 10-12 people
- ☐ 13-15 people
- ☐ 15+ people
- ☐ I don't know.
- ☐ I don't have anyone I could rely on.

33. How many people do you believe that you could currently rely on for medical support while aging?

- ☐ 1-3 people
- ☐ 4-6 people
- ☐ 7-9 people
- ☐ 10-12 people
- ☐ 13-15 people
- ☐ 15+ people
- ☐ I don't know.
- ☐ I don't have anyone I could rely on.

34. Have you thought about appointing someone to be your healthcare proxy or power of attorney in case of an emergency?

- ☐ Yes
- ☐ No

35. Have you appointed anyone to be your healthcare proxy or power of attorney in case of an emergency?

- ☐ Yes
- ☐ No

36. If you answered yes to the previous question, what is your relationship with that person?

- ☐ Friend
- ☐ Spouse / Significant Other
- ☐ Family (e.g., sibling, child, cousin)
- ☐ Other (please specify)

Definition of Long-Term Care and Long-Term Care Facilities

Long-term care refers to the medical and social services that are used to assist individuals with chronic health conditions in their daily activities. This includes, but is not limited to, institutional care provided by nursing homes, assisted living facilities, and continuing care retirement facilities; community care; and home care provided by family, friends, and professional service providers. Long-term care facilities are the facilities that provide care services and assistance to individuals in need of long-term care, including nursing homes, assisted living facilities, rehabilitation facilities, and chronic care hospitals.

You can return to this page at any point in the survey if you need clarification on what is meant by long-term care and long-term care facilities.

37. Do you believe that you will need to use long-term care services in the future?

- ☐ Yes
- ☐ No
- ☐ I don't know.

38. Do you believe that you will have to enter into a long-term care facility in the future?

- ☐ Yes
- ☐ No
- ☐ I don't know.

39. Have you considered using long-term care services within the past year?

- ☐ Yes
- ☐ No

40. How would you rate your knowledge of long-term care services?

Not Knowledgeable	Slightly Knowledgeable	Knowledgeable	Very Knowledgeable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

41. Do you believe that you or another LGBT person would experience any of the following at a long-term care facility because of actual or perceived sexual orientation and/or gender identity?

- ☐ Refusal of admission
- ☐ Abrupt discharge
- ☐ Attempted discharge
- ☐ Refusal of readmission
- ☐ Restriction of visitors
- ☐ Isolation
- ☐ None of the above
- ☐ Other (please specify)

42. Do you believe the faculty or staff of a long-term care facility would ever do any of the following because of your or another LGBT person's actual or perceived sexual orientation and/or gender identity?

- ☐ Refuse to provide basic services
- ☐ Verbally harass or ostracize you/him/her/them
- ☐ Physically abuse you/him/her/them
- ☐ Refuse to refer to a transgender resident with his/her/their preferred name or pronoun
- ☐ Refuse to let the spouse, partner, or person with the medical power of attorney or other health care directive make decisions for an LGBT resident
- ☐ None of the above

43. Do you believe that you or another LGBT person would experience verbal harassment or abuse by residents of a long-term care facility because of your/his/her/their actual or perceived sexual orientation and/or gender identity?

- ☐ Yes
- ☐ No
- ☐ I don't know.

44. Do you believe that the staff of a long-term care facility would deny you or another LGBT person medical treatment because of actual or perceived sexual orientation and/or gender identity?

- ☐ Yes
- ☐ No
- ☐ I don't know.

45. Do you believe that long-term care facilities in the South are more likely to discriminate based on sexual orientation and/or gender identity than those in other parts of the United States?

- ☐ Yes
- ☐ No
- ☐ I don't know.

46. How willing would you be to utilize the following long-term care services?

	Extremely Not Willing	Not Willing	Slightly Not Willing	Neutral	Slightly Willing	Willing	Extremely Willing
Home care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supportive housing programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nursing homes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Continuing care retirement facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisted care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

47. Would you be more willing to use long-term care services provided by LGBT people than those provided by non-LGBT people?

- ☐ Yes
- ☐ No
- ☐ I don't know.

48. Would you be more willing to enter long-term care facilities specifically for LGBT people?

- ☐ Yes
- ☐ No
- ☐ I don't know.

49. Would you be more willing to enter long-term care facilities for your specific sexual orientation and/or gender identity than a long-term care facility for LGBT people in general?

- ☐ Yes
- ☐ No
- ☐ I don't know.

50. How fearful would you be disclosing your sexual orientation and/or gender identity to the following individuals?

	Extremely Comfortable	Comfortable	Mildly Comfortable	Neutral	Mildly Fearful	Fearful	Extremely Fearful
Unknown providers of long-term care services (e.g., doctors, nurses, home care aides)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other individuals working in long-term care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Residents of long-term care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

51. Have you or a loved one who was LGBT previously used long-term care services?

- ☐ Yes
- ☐ No
- ☐ I don't know.

Previous Experiences with Long-Term Care

If you or someone you have known has previously used long-term care services, please answer the following questions. If not, scroll to the end of the page and click "Next".

52. Do you know of a person who has concealed their sexual orientation and/or gender identity in a long-term care setting or facility out of fear of discrimination?

☐ Yes

☐ No

53. Have you or a person you know ever experienced any of the following at a long-term care facility because of actual or perceived sexual orientation and/or gender identity?

☐ Refusal of admission

☐ Abrupt discharge

☐ Attempted discharge

☐ Refusal of readmission

☐ Restriction of visitors

☐ Isolation

☐ None of the above

☐ Other (please specify)

54. Has the staff of a long-term care facility that you or someone you knew lived in ever done any of the following because of a person's actual or perceived sexual orientation and/or gender identity?

☐ Refused to provide basic services

☐ Verbally harassed or ostracized the person

☐ Physically abused the person

☐ Refused to refer to a transgender resident with his/her/their preferred name or pronoun

☐ Refused to let the spouse, partner, or person with the medical power of attorney or other health care directive make decisions for an LGBT resident

☐ None of the above

55. Have you or a person you knew ever experienced verbal harassment or other abuse by residents of a long-term care facility because of your/his/her/their actual or perceived sexual orientation and/or gender identity?

☐ Yes

☐ No

56. Has the staff of a long-term care facility denied you or a person you knew medical treatment because of actual or perceived sexual orientation and/or gender identity?

☐ Yes

☐ No

Thank you for participating in this study. We appreciate your time completing this survey and hope to make services better for LGBT older adults in the future. We are happy to answer any questions you have about the study. You may contact us at lgbteldersht@gmail.com or our faculty advisor, Dr. Laura Hein (Hein@sc.edu), if you have study related questions or concerns. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at 803-777-7095.

57. Would you like to be considered for a \$50 Visa Gift Card and/or participate in a follow-up focus group based on the themes of this survey?

- ☐ Yes, I would like to do at least one of the above
- ☐ No, I would not like to do either of the above

To continue, please click "Next".

Participants who have completed this survey are qualified to enter a lottery for a \$50 Visa gift card. If you would like to enter a drawing for participating in this study, please enter an email at which we can contact you below.

58. Email Contact for \$50 Visa Gift Card Lottery

Email Address

If you would be interested in participating in follow-up focus groups based on the topics of this study, please enter an email at which we can contact you below. If you decide to participate, you will be invited to join in a group discussion about your perceptions of and/or any experiences with long-term care. In particular, we will discuss your thoughts about long-term care as an older LGBT adult in the South, experiences of discrimination, and perceived solutions to limit or improve those experiences. The focus groups will last approximately 90 minutes each and take place in 3 locations within South Carolina: Charleston, Columbia, and Greenville. Travel expenses will not be reimbursed.

59. Email Contact for Focus Group Follow-Up

City/Town

Email Address

We would like to once again thank you for participating in this study. We appreciate your time completing this survey and hope to make services better for LGBT older adults in the future. We are happy to answer any questions you have about the study. You may contact us at lgbteldersht@gmail.com or our faculty advisor Dr. Laura Hein (Hein@sc.edu), if you have study related questions or concerns. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at 803-777-7095.

If you are ready to submit your survey, please select "Done".

Appendix B

Interview Questions

Introduction:

Hello, my name is _____. I am a member of the USC research team for *Retiring to the Closet: Southern LGBT Elders and Long Term Care Facilities*. I am calling you in order to conduct a one-on-one interview for our research study. Is this still a good time?

Just to verify who I'm talking to, can you confirm the email that you used for the survey?

Informed Consent + Confidentiality:

This is a one-on-one interview designed to further explore your perspectives of long-term care services and determine your recommendations for improving long term care services for LGBT people. This interview will be recorded and transcribed, but all one-on-one interviews will be kept anonymous and will only be analyzed by members of the research team. The interview recordings and transcriptions will be kept in a secure location at the University of South Carolina. The results of the study may be published or presented at professional meetings or conferences, but any participant's identity will not be revealed. Only excerpts of the transcripts may be published.

- Do you consent to being recorded and interviewed for this study?
- Do you have any further questions or concerns before we begin?

Questions:

- Have you personally thought about what it would be like to enter long-term care as an LGBT person?
- Would your experience differ from non-LGBT elders? If yes, how so?
- How do you believe your experiences would differ if you entered into long-term care services/facilities in the South versus somewhere else in the country? *
- IF YES TO EXPERIENCES: What have your experiences been when interacting with long-term care services/facilities? *
- Do you have any general and Southern-specific recommendations that you would make to prevent discrimination against LGBT individuals in long-term care settings?