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As we age: listening to the voice of LGBTQ older adults

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ABSTRACT

The LGBTQ+ community is gaining long-overdue public health attention within the rapidly expanding demographic of older adults. As a group, LGBTQ+ older adults represent a range of diverse biopsychosocial needs and life experiences that may differ markedly from the general population. This has translated into health disparities experienced by this group and the emergence of policies calling for improved services for this community. In response, this qualitative study engaged ten focus groups (a total of 48 participants) throughout one mid-Atlantic state to better understand the experiences and perceptions of LGBTQ+ older adults regarding their expectations and needs as they age. Themes included (1) an emphasis on the nuance of connection as an aging LGBTQ+ adult; (2) a rich discussion of experiences with and expectations for quality of services as this group ages; (3) the realities of planning for future living arrangements as a member of this population; and (4) a clearer understanding of the two sides of advocacy for this group, as a personal responsibility and a call for allyship. Based on insights shared by participants, implications are discussed for improved and more visible engagement of this community within our health and human service sectors. We also affirm the need for greater attention from researchers and policy makers in respect to the whole health needs of this group. As a society and as professionals, we need to respond to these needs in better support of equity in the aging process for LGBTQ+ older adults.

KEYWORDS

LGBTQ+ aging; perception of aging; focus group; health disparities; needs assessment

As people are living longer across the globe, concerns are growing across multiple disciplines in the United States about how well its policies are prepared to support and care for its older adult population. It is estimated that the US population aged 65 and older will increase from 25.4 million in 2018 to 94.7 million in 2060 (Administration for Community Living (ACL), 2020). Advancing long, healthy, and productive lives is listed as one of the current Grand Challenges for Social Work. Over the next 10 years, social workers are called to: improve programs and services, focus on transitional employment initiatives, strengthen caregiver support, expand civil service opportunities, increase our research base on aging, reduce discrimination, and engage in more intergenerational programs (Grand Challenges for Social Work, 2018, p. 1) Social work clearly has a role to play in healthy aging across all levels of practice.

Meeting these Grand Challenges must involve a focus on minority aging, including recognizing the unique needs of different communities of older adults. The focus of this paper is to contribute to the growing understanding of the ways lesbian, gay, bisexual, transgender, and queer (LGBTQ+) older adults are a unique cohort within the older adult community. Specifically, the authors will discuss the

findings from a qualitative needs assessment of the aging and aging services for LGBT+ older adults in New Jersey. It should be noted that the acronym LGBT+ is used in this paper, and different variations (e.g., LGB, LGBT) are used in the reporting of other authors' research, however the participants in this study represent a subset of sexual and gender minorities, as shown in the sample demographics section below. For those readers who may be uncertain of some terms used throughout this article, a helpful resource for defining many of these terms can be found at the LGBTQIA Resource Center at UC Davis. Older LGBT+ adults were born in a time where homosexuality was criminalized, pathologized, and highly stigmatized. Impacts of this have been felt across the life course and continue to influence perceptions of care and services in older age. These experiences across the lifecourse, and their cumulative impacts, should be considered by social workers in order to provide holistic, ethical care to LGBT+ elders.

The research literature on LGBT+ aging was scant in 2011, when the Institute of Medicine (IoM) released a report entitled "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding." This report noted the lack of research on LGBT health in general and that even less research had been conducted on age related issues in the LGBT community. The IoM noted multiple areas of concern regarding elders, including: concealment of identity, depression, risk of suicide, poor general health, higher risks of certain cancers, and obesity, among several other factors (Graham et al., 2011).

In that same year, findings from the first national study of LGBT+ older adults were presented in the "Aging and Health Report" (Fredriksen-Goldsen, et. al, 2011). This first of its kind research was conducted across the country with approximately 2,500 participants, and documented high rates of victimization, higher rates of disability, less social support, less financial security, concealment of identity, increased risk for certain cancers, increased rates of depression, and suicidality in the sample.

These seminal reports opened the door for increased research interest in LGBT+ aging. Since these two publications, disparities have been further documented in multiple areas: seeking healthcare (Czaja et al., 2016), seeking housing (Equal Rights Center, 2014), self-reported frequent poor mental health, disability, obesity in women, and asthma (Fredriksen-Goldsen, et. al, 2013), elevated rates of HIV (Centers for Disease Control and Prevention (CDC), 2015), and HIV-related stigma (Slater et al., 2015).

This present study adds to the literature on LGBT+ aging by reporting on the first phase of a statewide health and social service needs assessment of LGBT+ older adults in New Jersey. The qualitative data collected in phase one is used to guide the development of a quantitative needs assessment instrument that will be distributed electronically statewide. This needs assessment data is an important step in challenging and transforming both the practice and policy environments in serving this population more effectively throughout the state. Statewide approaches to change are especially important targets given the ongoing and ignominious lack of federal protections for the LGBT+ community. This present study reports on the initial qualitative phase of the statewide needs assessment.

Literature review

Assessing the needs of disadvantaged and oppressed groups is a cornerstone of social work research, and informs the development of evidence-based practices and policies. The following section discusses the literature on the following with regards to LGBT+ older adults: 1) social work's role in serving this group, 2) needs assessments of this population, and 3) and the body of qualitative research related to aging and wellbeing.

Social work and older LGBT+ adults

Social workers have an important longstanding commitment to addressing health and service disparities for disadvantaged groups and this extends to meeting the needs of the LGBT+ community as

they age. The National Association of Social Workers (NASW) states that “social workers are key allies in the necessary efforts to ensure wellness, safety, and equity for all LGBT persons. Social workers have a shared commitment to promoting laws, policies and programming that affirm, support, and value LGBT individuals, families, and communities” (National Association of Social Workers (NASW), 2020, para. 1).

Erdley, Anklam, and Reardon (2014) highlighted the ethical imperative for social workers to develop practice competence in serving this population in a way that recognizes and incorporates the strengths and resilience of a community that has experienced much collective adversity. As this group is medically underserved and disproportionately prone to social isolation, there is an urgency in connecting them with appropriate supports. Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emler, and Hooymann (2014) have provided a solid foundation for social workers engaging in this important work by outlining core competencies for practitioners that seek to better serve the LGBT older adult community and their loved ones. These include guidance across many areas including reflective work for practitioners (e.g. examining personal biases), work for agencies (e.g. assessing and revising procedures and policies), and work for the profession (e.g. updating theories and tools, advancing a more inclusive policy agenda).

Social workers can be involved in collaborating with the LGBT+ community through community-based services that are explicitly tailored for this group, as exemplified by the Los Angeles Gay and Lesbian Center (Gratwick, Jihanian, Holloway, Sanchez, & Sullivan, 2014). Programming at this center focused on serving seniors in the community through social programming, case management services, and community education and awareness training. Specific to this last point of education and training, work by Rogers, Rebbe, Gardella, Worlein, and Chamberlin (2013) reflects efforts by social workers to elevate the voices of LGBT elders by enlisting them as active participants in designing and delivering training to future health care professionals. Training involved experiential exercises and elder panels to help deepen participants’ understanding of the lived experience of this group and were found to be quite effective based on evaluation of quantitative and qualitative participant feedback.

Maintaining a focus on training health care professionals, a variety of approaches and curricula are beginning to emerge. Social workers can be involved in development, delivery and evaluation of these trainings. For instance, Moone, Cagle, Croghan, and Smith (2014) examined delivery preference for cultural competency training surrounding care with LGBT older adults for service providers in Minnesota and found that providers: did desire training, preferred online delivery, and short duration was ideal. Social worker can be strategically involved in coordinating, facilitating, and evaluating training efforts at the agency level. Having state-specific data can help to tailor messaging in these trainings in ways that respond to specific and unique local needs.

Assessing the needs of older LGBT+ adults

Needs assessments are commonly used in social work to identify community needs. It is useful to begin by reviewing the literature on Local Area Agencies on Aging (AAAs). This is because they are mandated to conduct needs assessments in order to develop services targeted toward older adults with the greatest social and economic needs in their communities. While these plans are to be made with community input, little research has been conducted on how/if AAAs are including LGBT+ elders in their needs assessments and area plans.

Available research shows that improvement in assessing the needs of LGBT+ older adults is needed. For example, a study of roughly half of the 622 AAA Directors found that only 7.8% of AAAs targeted services to LGBT older adults (Knochel, Croghan, Moone, & Quam, 2012). Similarly, 75% of providers in the Michigan aging network reported offering no activities at all for LGBT older adults, while 56.3% did not conduct any outreach to the LGBT community (Hughes, Harold, & Boyer, 2011). This is unfortunate in light of needs assessment findings from North Carolina, which found that LGBT older adults’ perceptions of services in the aging network as ‘welcoming’ served as a protective factor against social isolation and eased the negative impacts of aging alone (Yang, Chu, & Salmon, 2018).

Portz et al. (2014) conducted qualitative interview-based assessments with Denver-based social service providers to assess their cultural competence in meeting the needs of local LGBT+ older adults. In their assessment they categorized only four of these agencies as “highly competent,” with 12 rated as “seeking improvement” and eight with the lowest rating of “not aware,” suggesting important ongoing work to be done in training service care professionals and transforming agency environments to better meet the needs of this population. Across areas of service design, delivery, and evaluation, needs assessment is an important tool social workers can use to honor our professional commitment to serving the LGBT+ older adult community with competence, humility, and respect.

A few local-level needs assessments of older LGBT+ adults have been reported in the literature. For example, a 2010 needs assessment in St. Louis (Morales, King, Hiler, Coopwood, & Wayland, 2014) examined barriers to care, comparing data from age cohort labeled Silents (defined as those born from 1925–1945) and Baby Boomers (defined as those born from 1946–1964). Findings showed that both groups considered the lack of LGBT support groups a barrier to getting needed services, as was the perception that adequately trained health and mental health practitioners are lacking. Moreover, both the Silent generation (39.4%) and Baby Boomers (47.5%) said that if health care providers found out their sexual orientation or gender identity, they feared they would be treated differently (Morales, et al., 2014). This mirrored the Aging and Health Report where 15% of LGBTQ+ elders reported fear of accessing health care outside of the LGBTQ community, and 8% still feared accessing health care inside of the LGBTQ community (Fredriksen-Goldsen, et al., 2011).

Studying LGBT older adults in North Carolina, Rowan and Beyer (2017) found that most participants had never used LGBT-focused services. However when participants were asked if they would be likely to use LGBT services, 48.8% said ‘a lot likely’ and 28.7% said they would ‘only’ use these services. The most requested LGBT services were recreation and social activities (e.g., art, cultural activities). Here again, local data mirror national data from the Aging and Health Report (Fredriksen-Goldsen, 2011), which indicated that only 28% of older LGBT respondents used any community-based aging services, but majorities of participants *wanted* services including housing, transportation, social events, support groups, and legal services.

Dunkle (2018) conducted focus groups with 31 lesbians and gay men in New Jersey to gauge their perceptions of services funded under the Older Americans Act. Many of the participants, aged 54–80 years old, had not heard of any of the OAA funded services. Those who had attempted to use senior centers reported non-welcoming environments (e.g., no LGBT specific programs, chilly environments) that prevented them from ever returning. A majority of participants had low expectations of a welcoming environment in any services for older adults. Many indicated that if they were mistreated, or even thought they might be, they would rather not use a service. Some insisted on being out to all providers while others expressed significant fear of being older, vulnerable, and out. Participants made a range of recommendations to service providers, including: agency training at all levels; taking it upon themselves to learn about unique needs and experiences of this group, and tapping into existing LGBT resources, when available. An example of this would be rather than “welcoming” LGBT older adults to a legal seminar at the senior center, have a legal expert come to the local LGBT center, where the focus can be on the often unique legal situations LGBT older adults face.

Qualitative experiences of aging for LGBT+ older adults

Qualitative inquiry can provide valuable insight as to how older adult services can be more accessible and acceptable to the LGBT+ community. Research activities like interviews and focus groups can offer an emic understanding of the lived experience of this group, which has likely informed both their needs and their perceptions of care

Recent qualitative studies have explored the perceptions of the older adult LGBT+ community toward aging and their anticipated needs as they age. These studies help to provide context for factors contributing to health disparities for this population and potential avenues for intervention. Czaja et al. (2016) conducted focus groups with gay men (74%) and lesbian women (26%), who were 50 years

and older ($M = 66.6$) and residing in South Florida ($n = 124$). Approximately two-thirds of their sample reported being single and around half reported living alone. Participants voiced concerns regarding vulnerability and fear that they would lack adequate caregiving support and access to other necessary resources as they age. Furthermore, they were concerned that when resources were accessed, they may be discriminatory or stigmatizing. While certainly not exclusive to the LGBT+ community, these elders also voiced fears about the potential for isolation and loss, but given the relatively high proportion of this sample that was single and/or living alone, these concerns take on new significance. While the sample was geographically confined and exhibited limited diversity, it does offer important insights into the lived experience of this group.

De Vries and Gutman (2016) highlighted the challenges that are often faced by this cohort in late-life and end-of-life planning, especially as they may experience increased needs but have limited supports due to decreased access to traditional resources. This can produce disproportionate distress and anxiety for the LGBT+ aging population when compared to the general population. In focus groups conducted with ($n = 23$) older adults in Canada, an overarching theme was that identity as an LGBT+ person was extremely important to participants. This identity was perceived to be in very real jeopardy as they aged due to heterosexual cultural norms, especially in institutions and other social relationships that they may come to depend on in later life (Wilson, Kortess-Miller, & Stinchcombe, 2018).

Specific to the perceptions of this population related to nursing homes and assisted living, Putney, Keary, Hebert, Krinsky, and Halmo (2018) conducted focus groups with 50 community-dwelling LGBT older adults in the Northeastern US. They found that participants were especially concerned with finding an environment that was explicitly inclusive, one that provided a sense of safety and fostered connection to the LGBTQ+ community. As was true in the Czaja et al. (2016) study, participants also voiced concern about judgment and discrimination from care providers in these facilities, especially expressing fear over having to be dependent on unknown others for their day to day existence. For some these worries amplified, “complex and intersecting dimensions of discrimination, violence, trauma, behavioral health, and suicide risk” (Putney et al., 2018, p. 897).

Van Wagenen, Driskell, and Bradford (2013) interviewed 22 LGBT+ adults, aged 60 and older regarding their perceptions of successful aging. LGBTQ+ older adults in this sample, characterized successful aging as coping with problems that did exist or coping with some effort, anticipating that hardships were part of the aging process. This is perhaps not surprising given the adversities that this age cohort has faced collectively. This comports with the Minority Stress model (Meyer, 2003) wherein these experiences are an extra layer of stress experienced by minority groups over and above what the general population experiences.

Study aims

The goal of this study was to explore what LGBT+ older adults thought about aging and their needs as older adults now and in the future. Questions from the semi-structured interviews related to where they saw themselves living as they got older and any worries or fears they had about aging in place or not being able to live on their own at some point. Participants were also asked to discuss their perceptions of LGBT+-specific aging services, the need for competency trainings amongst service providers, and their general experiences in healthcare settings as an LGBT person. Qualitative data gathered represent the first phase of a statewide needs assessment.

Methods

Study design

Focus groups were selected as a qualitative approach to data gathering for this study to aid researchers in identifying the most salient issues facing this population. These themes will be used in the future to

develop a quantitative needs assessment instrument. Padgett (2008) refers to this as sequential design, suggesting that, “the ecological validity of a quantitative study can be enhanced considerably by grounding the study in qualitative interviews and observation before and/or after” (p. 224).

Sampling plan

Purposive sampling was used in this study. Persons who identified as lesbian, gay, bisexual, and/or transgender, and who were at least 55 years of age, were invited to participate. We engaged in recruitment via multiple avenues for this study. A prominent state-wide LGBT+ advocacy organization was a strategic partner in this research. This organization advertised for focus group participants on its many social media platforms along with sending e-mails to its extensive listserv. Next, other LGBT+ advocacy and support organizations across the state were identified, contacted, and asked to send a flyer to their e-mail distribution lists and share information on their social media platforms. Because New Jersey consists of multiple counties without such organizations, researchers contacted the leaders/advisors of LGBT+ groups at state colleges and universities and asked for recommendations/leads and if they could share study information at their school.

Additionally, in areas without LGBT+ resources known to us, churches that self-identified as ‘welcoming’ to the LGBT+ community on their websites were asked to share flyers with their congregations via newsletter or bulletin board. Researchers also placed a study flyer in a monthly newsletter for older adults sent by a university located in a rural part of the state. Flyers were distributed at two Pride celebrations, one in the central part of the state, and one in the southern part of the state. Lastly this study utilized snowball sampling, inviting all participants to share study details with their social networks. This approach had at least some impact as 10 participants contacted the researchers after someone they knew participated in a focus group.

Description of sample

A total of 48 older adults, ranging from 50 to 82 years old ($m = 66.7$) participated in these focus groups. All participants were asked to self identify. In terms of sexual orientation, 34 identified as gay, 12 as lesbian, 1 as pansexual, and 1 as heterosexual (this person listed autogynephilia as gender identity). For gender identity, 30 identified as man or male, 12 as female, 1 as transgender, 1 as gender fluid, 1 as transitioning. With regards to race/ethnicity, 39 participants identified as white, 5 as Black, 3 as biracial, and 1 as Latinx. Of participants who responded with their relationship status 5 identified as married, 13 partnered and living together, 5 partnered but not living together, 22 identified as single, and 1 as widowed.

Data collection

A total of 10 ten focus groups were conducted for this study in Fall 2018, ranging in size from two to eight participants. Focus groups were facilitated by a trained moderator (the study principal investigators, which included two PhD holders, one MPH, one MSW) who asked open-ended questions. The moderator used a semi-structured interview guide. Marshall and Rossman (2006) indicated that focus groups have several strengths that were relevant to this study. For example, they state that focus group discussions are useful when exploring a topic that participants may have not thought a lot about. Rather than a one-on-one interview where the participant may not know how to answer the questions, group dynamics can facilitate a more natural flow of conversation with others similar to the participant. This more relaxed environment allows for the free flow of information and flexibility to explore relevant topics outside of the interview guide.

The semi-structured interview guide was developed by the study principal investigators (see attached). The selected topics for the interview guide were based on literature on LGBT+ aging (Fredriksen-Goldsen, 2011; Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emlet, 2015), the Health

Equity Promotion Model (Fredriksen-Goldsen et al., 2015) and literature on aging service providers and LGBT+ elders (Levy, et al., 2014; Yang, et al., 2018).

Focus groups were conducted at LGBT+ advocacy organizations, participants' homes, a federally qualified health center, a university conference room, and a Jewish community center. Each participant gave informed consent that included permission to audio record the discussions. Confidentiality agreements were also signed to ensure discussion would remain 'inside the room' and encourage participants to speak freely. All data collection procedures were approved by two university IRBs.

Data analysis

All focus groups were audio recorded and transcribed verbatim. No qualitative data analysis software was used in the analysis procedures. Thematic analysis began with a process of open coding of the first 3 manuscripts by a team of 4 coders. After individual open coding was complete, the coders met, reviewed and compared codes, and converged on an initial code structure that was utilized to examine the transcripts from all focus groups (including the initial 3). When all transcripts had been coded using the preliminary coding structure, the group met in subsequent sessions to compare what data each code contained and any data that did not fit the existing structure. Based on these collaborative meetings, themes were defined and dimensions within each theme emerged. Once the team's analysis was drafted, findings were shared with 10 of the focus groups participants via e-mail to provide member-checking to support the accuracy and authenticity of the findings. This approach to thematic analysis was primarily inductive as it is based on emergent themes from the data vs. an a priori, theory-driven coding structure (Braun & Clarke, 2006, 2012)

Results

Theme one: the nuance of connection as an aging LGBT+ adult

Connection emerged as a prominent theme with several sub themes. While the need for connection and socialization is not unique to the LGBT+ community, participants suggested there were nuances to this sense of connection that were specific to being an LGBT+ older adult. This sense of connection was defined as participants' desire to feel connected to other people as part of a network that allowed them opportunities to participate in a range of meaningful social activities and to experience a sense of comradery with others who have a shared history. As one participant expressed, "Our lives, our lives history have been different. We'll each have gone through the process of coming out, and that alone, is something shared that creates a bond of interest" (focus group 3).

One subtheme in this area was the range of social network density experienced by participants and its perceived significance. This represented a range of social needs within this population. Some participants described vibrant social networks, replete with friends and family,

We've also cultivated friendships from every decade, from [our] 20's all the way up to [our] 70's, so that's really cool to because . . . [we are] interacting with people from different generations gives us different perspectives and some of them are gay and some of them aren't (focus group 6).

Others identified feeling relatively isolated or that current relationships offered limited or superficial social support. For example, one participant stated,

I think that we are woefully without family or nieces and nephews . . . And you can't count on just one person in your life (focus group 6).

Especially salient to participants were their relationships with their family of origin. Some expressed that they have very supportive families who are actively involved in their lives and committed to caring for them as they age. For example, one participant shared,

I've also got between six to 10 cousins in the area that have offered to be there for me if I become incapacitated or something happens to me and they'll take me in. So, I'm always going to be around family which is a priority for me (focus group 3).

However, other people described much less supportive relationships. "And Pop, I just remember him trying to disown [me] . . . They both (parents) thought I was doomed to hell" (focus group 7). Having a history of isolation can reinforce future fears was also a subtheme in this area. The fear of isolation and aging alone that is experienced by many during the aging process seemed to be compounded by a history of relational loss and feelings of disconnection that were often connected to participants' coming out process. "Before, you got ostracized by your family, you got ostracized by your friends, you got ostracized by everyone" (focus group 7). These experiences could also be a barrier to forging new relationships in the present.

When we're growing up and somebody knew we were gay, we were going to be beat upon and made fun of. I remember some of that . . . I'm assuming that the younger generation has it a little bit easier today, so as they age, they may not have the same problems . . . isolation that we have as an older gay person (focus group 3).

A final subtheme was the importance of finding places and people that affirm. Many participants expressed a need for more social programming targeted to and tailored for the older LGBT+ community. "I mean, it would be great if in every county there was a place where the LGBT+ community, have a place to go that's friendly. Not every county has that . . ." (focus group 2).

This was especially true as participants have felt a shift in LGBT+ culture.

And so what happens here in suburbia, is that we end up with people who are fragmented. Our community is grossly fragmented. We no longer have the clubs, or restaurants, or other places to go, and as an aging organization, we can't afford to send newsletters out to everybody every month (focus group 4).

Finally, it is important to note that not all participants felt a strong sense of connection and camaraderie with the LGBT+ community.

I feel more alienated against the LGBT community, only because I have been noticing the meet-ups . . . (are) usually around . . . alcohol . . . I don't do alcohol . . . it's what they call the "cookie cutter" type LGBTQ+ people. Everybody has to do the same thing, so if you don't do the same thing, there's something wrong with you (focus group 1).

This theme exemplified the richness and resilience of social connection experienced by many participants with robust connections to both chosen and biological families, but also a haunting sense of isolation that has colored both their past and their outlook on the future. Acknowledging this wide continuum and forging new opportunities to acknowledge and affirm aspects of their LGBT+ identity through social connection seemed to be important takeaways from participants' messages.

Theme two: experiences with and expectations for quality of services

The second theme to emerge from the study related to quality of services, defined as participants desire to receive services that are committed to honoring who they are as an individual, as part of a family, and as members of the broader LGBT+ community. This commitment is demonstrated at the level of provider and at the organization/agency/facility level. Participants expressed a range of preferences for receiving services. Some advocated for exclusively LGBT+ services, some for integrated (LGBT+ affirming), some for LGBT+ identifying (providers), while others had no preference.

The doctor I knew was an out gay man. The sky opened, the sun came, angels sang. [He] spoke native Gay . . . Not somebody who has Modern Family version of what gay speak is. Somebody who actually understands and knows first-hand and doesn't have to translate (focus group 4).

For other participants, the primary issue of importance was knowing a provider was accepting of LGBT+ people. Several participants expressed a need for some type of reference guide for their area. "If there was some designation where you knew, when you're getting that insurance book and you're

looking through all the doctors and you had some indication of who's gay exactly and what not, that would be very valuable" (focus group 2). Another participant agreed:

Whether you're talking about a doctor or whether you're looking at even at visiting aides, you've got to know that they're gay friendly. I mean, that's a requirement. Because you certainly can't even have somebody come into your home, if you can't trust them (focus group 2).

Not all participants felt this was of utmost importance. "I don't see why they have to be LGBT specific. Just programs for older adults and if you're gay you take part, if you're not interested, you don't, and that option is for straight people too. What [is the] difference" (focus group 6)?

Another sub theme was the issues of disclosure of one's sexual orientation to service providers. This is another area where perspectives varied. Some indicated they were always out, while others were much more hesitant.

I've heard a lot of commotion about doctors not treating you and not helping you if they found out you were gay, so I kept that quiet. Up till now, nobody knows. So, they've been helping me. I've always wanted to say, "listen, I'm gay. Is there any problem?" But then I figure, well, if I do that then I'll lose a doctor. And doctors are very important to me right now . . . and it bothers me a lot, because it's been four years now that I've come out, and the torture that I went through when I was a kid for being gay, is still hurting me (focus group 2).

I want to break the barrier that keeps fortifying the stigma. That's why I walk in and announce my sexual orientation up front, because I'm not ashamed of it, so if it's a doctor that has a problem with it, I throw the ball in their court (focus group 4).

There was also a firm belief that nondiscrimination is not enough. Participants explained that nondiscrimination policies do not, of themselves, create an educated and inclusive environment. "We would like to know what organizations are doing so that we would be able to feel comfortable" (focus group 6). Discussion centered around the idea that a proactive approach must be taken by providers to learn about LGBT+ issues and providers must create an environment where LGBT+ people are part of the fabric of the place, not just a tolerated minority.

I would want to look for a facility that I knew not only would accept the fact that we are gay, but that had other gay residents. Because when you have spent most of your adult life hanging around with like-minded people . . . It makes that making new friends thing much easier, knowing that there's programming or other people in the facility (focus group 5).

Another salient point of discussion here was the fear of going back into the closet. Many worried that they might have to hide their identities as they age to stay safe or be accepted. Fear of this was already causing participants stress and anxiety.

I don't know if it's a matter of creating a whole new environment, but just making sure that LGB people who, when we're at this threshold of their life and they're transitioning with these services, they don't find themselves isolated. And, that it's inclusive, and they don't have to feel they have to go back in the closet at 70 years old because now they're living in a public senior housing facility. So, I think, again, part of it is just acceptance and education in making sure that everything is a welcoming space (focus group 2).

Theme three: living arrangements

The discussion around living arrangements centered on a need for awareness of and practical access to a continuum of living arrangements that would allow participants to live authentically. Along with this, many expressed a need for assistance in considering options and how these might align with their resources, supports, values, and wishes.

There was a great deal of fear about the future for many participants. As with many older LGBT+ adults, multiple participants did not have biological family, were not partnered, and were concerned about the possibility of aging alone.

I don't have children. I'm the youngest sibling. Um, I don't really have, I mean, I have nieces and nephews, but I don't see anybody wanting to take care of me. And so, I see myself in a nursing home, and it's very, very discouraging and I don't know . . . I mean, there's nothing I can do about it (focus group 7).

Others were feeling secure and "okay" currently, but there was a good deal of worry about the future. "Who is going to take care of me" was a common question asked by participants who were not partnered. In addition to those who were not partnered/single there were multiple concerns raised by those who had lost partners and spouses, oftentimes recently. "I don't wanna be alone and that worries me because I am alone. I don't have any close friends; Bill was my best friend. Now I'm trying to establish friendships and at 75, I'm finding it very difficult" (focus group 3).

Another issue of importance was being able to live a full life as they age as LGBT+ individuals in whatever living arrangement they chose. While many Americans have trouble viewing older adults as sexual beings, some spoke about the particulars of having same-sex relationships in residential facilities. Said one participant, "if we're talking about moving into a care facility where we may be single at the time, but we still have attractions or affection needs . . . I don't know how many facilities are prepared to handle that" (focus group 4).

Discussion of optimal living arrangements meant not only finding an environment free of institutional discrimination, but full acceptance in the environment through the presence of other LGBT+ people. As one participant stated,

If I was in a nursing home, I'd want there to be at least a weekly meetup for the LGBT members, residents of the home. Our lives, our lives history have been different. We'll each have gone through the process of coming out, and that alone, is something shared that creates a bond of interest. I guess I could carry around pictures of nieces and nephews and great nieces and nephews, so that when people take out pictures of their children and grandchildren to talk with each other, I could do that also (focus group 3).

Many participants had heard "horror stories" about negative experiences of LGBT+ older adults in a variety of living arrangements. These negative experiences heightened anxiety about participants' own futures. One participant shared the story of a lesbian friend who moved into a 55+ community and is afraid to be out to her new neighbors. "She comes home from work, she goes into her apartment and she locks the door . . . That's gotta be, um, an awful kind of way to live your life" (focus group 8). Another participant shared that he had a friend that moved into an apartment building for those 65 + . An openly gay man in other areas of his life, this friend is now,

Extremely frightened that his 157 neighbors will find out that he may not be heterosexual. Extremely frightened. And he has reason to be, because he hears what the other residents are saying . . . he hears them coordinating Bible Study classes, hears them talking about "the gays," hears them talking about all of these very hostile topics to him. And he cowers, he shrinks and will hide in his apartment. Won't stand up for himself. He's afraid because he's so outnumbered. After living in a single-family home all of his life, now, as he's pushing 90, he's got 150 people around him that he doesn't know that he can trust (focus group 4).

Theme four: the two sides of advocacy

Advocacy was a final theme and one that encompassed various aspects of all others. Advocacy was about both personal responsibility (self-advocacy) and necessary support from others. The need for advocacy was perceived as especially important in the presence of historical and contemporary political forces that made rights within the LGBT+ community often experienced as impermanent and tenuous.

Being civically involved and embracing activism was seen as vital by many participants as members of the LGBT+ community. This included acts like voting, "So I think that that's another issue that we need to get aware of is getting people who aren't heterosexual, no matter whether they're lesbian, gay, bi, or whatever to vote" (focus group 5). It also meant forging and supporting relationships with politicians who were supportive of LGBT+ rights.

I think it's also important . . . when a local or a county politician makes a statement or takes a stand in favor of the gay, lesbian and transgender movement, that you write an email to them, write them, express your appreciation . . . it's our obligation to say, "Thanks for taking a stand for minorities" (focus group 4).

This activist identity shared by many was grounded in a shared history in the fight for rights and recognition. "They were denying us our or civil rights by not allowing us to get married" (focus group 5). "I was amazed to see that things did get changed eventually but it was, it is an uphill battle" (focus group 8). This was poignantly stated in one account,

I lived in the closet for so long that I didn't have the camaraderie like these women all do because I didn't come out until 20 years ago and then it was slow. It's different and now that I have that kind of freedom, I'm not about to give it up (focus group 5).

However, this fight has come at a price. Some people acknowledged that they were tired and that this fatigue could mean losing autonomy, an unnerving prospect.

I'm tired of fighting. I fought in 1980 . . . I marched and I've raised money and I did this, and I did that. I can't do it anymore. I can fight with my money, but I can't physically do this stuff that I did anymore. So, I feel like I have less of the control on what's actually getting fought for (focus group 8).

Despite being weary, the need for active involvement in political action and advocacy work felt especially pressing in our current times. While many participants acknowledged the progress they have seen in their lifetimes with respect to LGBT+ rights, they were disheartened by recent political and legislative changes and very wary of what this might foreshadow. "I think that we really have to connect too, because . . . we're seeing how things are changing. In two years, the laws . . . [have gone] backwards, yeah . . . backwards. I feel like we're all back in a closet, I really do. Um, it's very sad" (focus group 7). This was a sentiment shared by many.

It doesn't make you feel like you're validated as a human being. You are, are an exception . . . You feel like you're being erased again after, after having to fight for everything . . . now it's like they are taking it away again, can they take it away, are we grandfathered in, what's gonna happen (focus group 8)?

Due to many of the experiences and concerns of older adult LGBT+ persons, there was a sense of hypervigilance in monitoring and taking precautions to safeguard their rights. "I think this is where there's a uniqueness among the LGBT aging versus the general population aging, is that we're concerned about government regulations are going to impact us adversely . . . denying our existence or taking away these (benefits and entitlements)" (focus group 8).

Finally, the need for advocacy was not perceived to be uniform. For instance, it varied based on where one lived. Many participants identified that they felt fairly supported and accepted where they lived, but worried about people in more rural or isolated parts of the state. Furthermore, participants cited that "there's still 29 states where you can be fired for being gay . . . and there are still 10 nations in the world where you're gonna be put to death for being gay" (focus group 7), recognizing the lack of universal protections and support. In addition, other aspects of people's intersectional identity may make experiences of oppression (and the need for advocacy) more acute.

Um, no, not in the black community, in the black church. They . . . they treat me nice, but they won't . . . won't let me do anything . . . But, you know, it's tiring because at some point you're just, you're . . . you're going there and you're being nice and everything and you see that they're, like, overlooking you for everything (focus group 7).

Discussion

This study utilized focus groups in an attempt to better understand the perceptions and needs of LGBT + older adults across a mid-Atlantic state. Themes from these focus groups offer important insights shared by participants regarding their unique and nuanced aging experience. These findings will inform development of a quantitative needs assessment tool, but also stand as valuable guidance in their own right.

Many participants discussed a lack of social connections as they age, especially social connections that affirmed their LGBT+ identity. Many stated the bars that had been a significant part of their younger lives were either closed or not the type of environment they now prefer. Participants from multiple counties in the state had no LGBT+ resource centers or ways to connect with each other at all. This is consistent with emerging research on this population. For example, Fredriksen-Goldsen, et al. (2011), in their national study of Elders, found that 59% lacked companionship, 53% felt isolated from others, and 54% felt left out (p. 34). In a qualitative study conducted by Perone, et al., (2020) LGBT+ older adults also experienced isolation and challenges with creating and/or maintaining social connections within the LGBTQ+ community. It was reported that “nearly all of the participants” wished for “support and connection” (Perone, et al., 2019, p. 131).

This is an opportunity for AAAs and other agencies serving older adults to develop socialization opportunities targeting this population. As an example, the state of Massachusetts funds many targeted programs, such as dinner clubs, brunches, teas, dances, potlucks that were available before COVID on most days of the month. Also, there are state-funded LGBT bereavement groups, which are free to participants and run for 8 weeks (Fenway Health, 2020).

As with many older adults, participants in this study expected to have increased interactions with service providers as they age. However, LGBT+ participants have to navigate finding services that 1) are knowledgeable about their unique needs and 2) specifically seek to create welcoming environments. This is crucial, because data that suggests LGBT+ older adults disproportionately delay or avoid seeking services that could potentially improve the quality of their life as they age (SAGE, 2010). Fredriksen-Goldsen, et. al (2011) found that 15% of study participants feared accessing healthcare outside of the LGBT community, with 13% having been denied healthcare or receiving inferior care due to being LGBT.

Competency in understanding this population was valued by study participants, but it was not seen as sufficient if not accompanied by visible signs (e.g. inclusive language and documentation, affirming bedside manner, diverse programming) that the needs of this group matter. Based on this finding, state departments or divisions of aging could require that state-funded services receive mandatory training on service needs of this population. We have begun to see states take action by requiring mandatory training in LGBT+ awareness for those providing services to older adults (Fenway Health, 2018). As social workers we need to advocate for advancing these types of legislation to every state and across settings where older adults receive services. Furthermore, we need to ensure that these mandates are upheld.

Aging alone and/or the need to negotiate future changes in living arrangements is also a common concern of many older adults. However, as participants in this study discussed residential care options, it was clear that there were unique worries, such as how accepting these environments might be. This included receptivity of both staff and other residents toward LGBT+ individuals and relationships between LGBT+ residents (e.g., cliques). Housing was identified as a prominent concern of LGBTQ older adult participants of a qualitative study in Denver (Boggs et al., 2017). They expressed a strong preference for staying in their neighborhood, however, realizing that they may need to move to a communal or assisted living situation in the future, they expressed a desire for exclusively LGBTQ older adult options. Based on the apprehension and relative lack of planning around future living arrangements that many participants in our study reported, AAAs should consider how to engage the LGBT+ older adult community in more active discussions about future care planning and help them to explore and consider what options may best meet their needs as they age. Other studies have reported perceived fears of elders if they were to disclose sexual orientation in assisted living facilities that included fear of abuse by staff, isolation from other residents, discrimination by other residents, and discrimination by staff (National Senior Citizens Law Center, 2011). Qualitative research by Dunkle (2018) found elders worried about being out and poor treatment in facilities, with one person stating, “I wouldn’t tell them because I don’t know what would happen to me . . . you could be 90 and perfectly lucid but frail. And you know when someone is not taking good care of you and that is why I would not say it” (p. 451).

Collectively, LGBT+ older adults have a rich history of advocacy and civic action. This generation is often referred to as the Stonewall Generation. However, the need to continually fight for their legal rights left some participants socio-politically fatigued. Many feared the loss of civil rights, despite a lifetime's work to win them and wondered who was going to advocate for them as they age. SAGE tables, which were created to combat loneliness and isolation, build intergenerational connections, and find and sustain friendships as people age (SAGE, 2019). Hosting or supporting a table is an easy way that AAAs and others can support the older LGBT+ adult community. This is simply a meal shared between older and younger LGBT+ adults. These can afford opportunities for older adults to explain their involvement in the LGBT+ civil rights movement and encourage the younger generation to be both happy for the gains made and aware of the need for vigilance and continued political action. All one needs to do is host a meal. Register as a host with SAGE and they will send a planning and conversation guide. AAAs could host these in the local community quite easily (SAGE, 2020).

Findings from this study are consistent with the Health Equity Promotion Model (Fredriksen-Goldsen et al., 2014). This model recognizes that both structural (stigma, exclusion) and individual experiences (discrimination, victimization) have a significant impact on wellbeing. For older LGBT+ adults, this understanding is coupled with an understanding of their experiences across the life course and intersectionality. Participants in this study were impacted by both structural and individual experiences. Psychological impacts were most discussed, where constantly being on guard for discrimination and expecting non-welcoming environments was chronically stressful. Part of this chronic stress had to do with their life course experiences. This lived through multiple decades of legalized discrimination, the AIDS epidemic, and various forms of interpersonal rejection. Understanding this through a life course theory lens allows us to understand the cumulative impacts of these decades on health. Lastly, intersectionality allows us to see experiences through participants' multiple identities. In one focus group, Jewish men could only view LGBT discrimination through the lens of the Holocaust. African American participants talked about constantly wondering if they were being treated poorly because they were Black or gay. These experiences were described as keeping participants hyper alert, which is detrimental to health.

Strengths and limitations

There are several notable limitations to this study. In regards to the sampling bias, those who participated were out, generally not socially isolated, and younger (within the older age group designation). This meant that perceptions of those who are hidden in the community, those who experience social isolation, and those who are older were not captured. These groups may have much different experiences with aging, as well as different needs for care. In addition, there was also limited representation of the following in the study sample of people who identify as transgender, persons of color, and those with lower SES.

A strength of this study was the use of focus groups. Providing a safe space for LGBT+ elders to congregate and share their past experiences as well as concerns for the future allowed this study to capture rich data. As Patton (2002) notes, focus groups are useful in needs assessment research and can "provide safety in numbers for people in vulnerable situations" (p. 389). Another strength of this study was the use of multiple strategies for rigor, including member checking, observer triangulation while assessing for themes, and interdisciplinary triangulation by including researchers in the fields of social work and public health.

Implications for social work

LGBT+ elders have lived through years of state sanctioned oppression and discrimination. While not always visible due to safety concerns, it is estimated that this population comprises approximately 2.7 million people and will grow as the baby boomers continue to age into this demographic. However, for many of this cohort, their past experiences of marginalization have created fear and a sense of need to continue to protect their private lives from scrutiny despite gains made in legal protections and

public awareness. This has been especially true in the current tumultuous political climate with a lack of federal protections and many ongoing threats to LGBT+ rights at the state level (American Civil Liberties Union (ACLU), 2020). Living out and proud can feel like a precarious freedom at best and at times more like an elusive pipe dream for many.

Conversely, the resiliency of this cohort is undeniable. Despite the lack of legal protections, and frequent exposure to oppression and discrimination, this community has developed formal and informal networks that have provided care and support when the state, family of origin and faith communities abandoned and/or denied their basic rights to be acknowledged as human beings and to be cared for accordingly. Furthermore, they represent a dynamic and formidable advocacy force that has coalesced, fought for, and won many basic human rights despite blatant structural oppression.

Social workers need to be partners in this ongoing fight. As social workers we are especially concerned with both the personal and public health needs of marginalized groups, including LGBT+ older adults. This needs assessment points toward many ways in which social workers can honor our duty across many levels of practice to advocate for knowledge, education, services and protections for this underserved population.

Partnering to understand and engage diversity

Ongoing research exploring the experiences and needs of this community is required, especially in respect to intersectional identities across diversity in economic, geographic, racial, gender identity, and abilities. As previously discussed, despite concerted efforts, this study struggled to engage broad representativeness in our sample. Participants still voiced concerns statewide that LGBT+ community members with multiple oppressed identities (e.g. transgender, BIPOC, economically disadvantaged, geographically isolated) faced much greater disadvantages. As a research community we need to continue to consider innovative and empowering ways to engage the least represented of this already underrepresented community.

Providing culturally responsive services

At the state level, findings like these can be used to assist AAAs in the creation of welcoming programming in senior centers and *reaching in* to local LGBT+ communities to assess programming wishes. Social workers can play meaningful roles to support this work, such as networking between existing older adult services and established community resources (e.g. social groups, LGBT+ advocacy networks, LGBT+ cultural events and organizations).

We also need to continue to advance the quality of existing services. Data from this needs assessment will be used to advocate for training of Area Agencies on Aging (AAA) personnel and their contracted providers. Ongoing efforts are required to develop, evaluate and disseminate effective trainings and policies that support the wellbeing of this population. This work needs to assess both the competence of providers in meeting these needs, but also the climate of the institution and its ability to outreach, engage, and sustain a welcoming and affirming spaces for LGBT+ older adults to receive services. This can build on emerging research (e.g. Croghan, Moone, & Olson, 2015; Kim, Wilson, Biery, & Frutos, 2019) and resources ((e.g. American Medical Association's (n.d.) *Creating an LGBTQ+-Friendly Practice*; SAGE and the National Resource Center on LGBT Aging's SAGE (2015) *LGBT Programming for Older Adults: A Practical Step-by-Step Guide*)) that we are beginning to see in this area.

Advocating for inclusion and representation

With regards to policy aims, data will be used to advocate for LGBT+ inclusive language in the Older Americans Act. In March 2020, the OAA was reauthorized and did, after years of advocacy, add language that will require State Units on Aging (SUAs) and AAAs to ensure they collect data from their local LGBT+ communities and confirm they are meeting needs identified in this data

collection (Services and Advocacy for GLBT Elders [SAGE], 2020). This is a valuable step forward to ensuring that LGBT+ older adults are considered *those with the greatest economic and social need* under the OAA and that all parts of the OAA become LGBT+ inclusive (Administration for Community Living (ACL), 2020). In addition, Area Agencies on Aging (AAA) must begin to ask and collect data on LGBT+ elders use of and satisfaction with the services that they provide, especially as the census bureau excluded individual questions regarding sexual orientation and gender identity.

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