

7-13-2018

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## Recommended Citation

Seelman, Kristie L.; Lewinson, Terri; Engleman, Lily; and Allen, Allex, "Motivations for Advance Care and End-of-Life Planning Among LGB Older Adults" (2018). *Social Work Faculty Publications*. 85.

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Motivations for Advance Care and End-of-Life Planning Among LGB Older Adults

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This is the Author Accepted Manuscript of a manuscript in press with *Qualitative Social Work*. The version of record is available at <https://doi.org/10.1177/1473325018792396>

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Dr. Seelman's time on this project was supported by the National Institutes of Health Loan Repayment Program for Health Disparities Research through the National Institute on Minority Health & Health Disparities.

### **Abstract**

Lesbian, gay, and bisexual (LGB) older adults are more likely than their heterosexual peers to experience health disparities, discrimination from healthcare providers based on sexual orientation, and rejection from their family of origin, all of which can complicate medical care and decision making, as well as end-of-life arrangements. Yet, relatively few studies of LGB seniors have looked at motivations for advance care and end-of-life planning, which are strategies that can help ensure that healthcare treatment and end-of-life wishes are enacted as desired. The present qualitative study investigated this topic with a purposive sample of nine LGB and same-gender-loving adults in a metropolitan region of the Southeastern United States. The study involved in-depth face-to-face interviews, followed by a brief pen-and-paper survey. Participants' ages ranged from 65 to 77; the sample included five men and four women. Six individuals were white/Caucasian, while three were African American/Black. We identified three themes related to motivations for advance care and end-of-life planning: wanting a sense of agency, learning from others, and reducing conflict and confusion for loved ones. We discuss the importance of these findings for social work practice with LGB older adults and for social work education, as well as implications for future research.

*Keywords:* advance care planning; end-of-life care; gay; lesbian; bisexual; older adults

Lesbian, gay, and bisexual (LGB) older adults face unique situations that can complicate aging-related healthcare services and end-of-life care, including experiencing discrimination from service providers related to sexual orientation (Fredriksen-Goldsen et al., 2011; Orel, 2014), being rejected by their family of origin (Czaja et al., 2015), being less likely to be partnered or have children who can care for them (Fredriksen-Goldsen et al., 2011; Gates, 2011), and experiencing a number of acute and chronic health conditions as well as functional health challenges at greater rates (Fredriksen-Goldsen, Kim, Barkan, et al., 2013; Seelman, 2018). Given these factors, this population may benefit from engaging in planning about healthcare treatment and end-of-life arrangements as a strategy for proactively managing aging-related care and services. Yet, few studies have looked in-depth at advance care planning among this population, including their motivations for planning. The present study intends to address this gap in the literature. Before detailing our study, we will first discuss research on advance care planning and unique factors related to LGB aging and end-of-life care.

### **Literature Review**

Advance care planning is intended to encourage an individual to reflect upon and put into writing one's needs related to aging, desired healthcare treatment, and end-of-life care and arrangements. The intention for such planning is to better ensure that one's preferences are respected and adhered to by family and helping professionals. *Advance care directives*, a more specific term, generally consist of three legal documents: (a) a last will and testament, which states how to distribute one's property after death; (b) a living will, which indicates one's preferences for healthcare treatment should one be unable to articulate one's own wishes after developing a critical illness; and (c) a healthcare durable power of attorney, which indicates who should make decisions about one's healthcare if one is unable to contribute to such decision-making (Boehmer, Clark and Sullivan, 2010).

Past research indicates that advance care planning: (a) promotes adherence to the treatment preferences of patients who are no longer able to make decisions for themselves, and (b) provides psychosocial benefits for patients' loved ones involved in end-of-life decisions. In a randomized controlled trial among inpatients age 80 and older in Australia (Detering, Hancock and Michael, 2010), those assigned to the advance care planning intervention were more likely to have their end-of-life wishes known and respected, they or their families reported greater satisfaction with the quality of death, and their families experienced less stress, anxiety, and depression than those in the usual treatment group. Yet, in a summary of research studies, Kass-Bartelmes and Hughes (2004) document low rates of advance care planning even among patients with severe or terminal conditions and note that care plans were often not very precise or were not adequately translated into treatment by medical providers or patient surrogates. Although many patients are interested in learning about advance care planning, they may mistakenly believe that it is mostly for people who are close to death (Kass-Bartelmes and Hughes, 2004).

LGB older adults can face particularly complex decisions related to planning for aging-related healthcare and caregiving, financial stability, and end-of-life arrangements, which suggests that advance care planning may be particularly useful to this population. Research indicates that LGB older adults are less likely to have partners in older age (Fredriksen-Goldsen et al., 2011) or to have children to care for them compared to heterosexual adults (Gates, 2011). Older LGB adults often turn to friends and "families of choice" for social support and caregiving assistance (Muraco and Fredriksen-Goldsen, 2011); such preferences may not be clearly stated before facing a health emergency, putting healthcare providers, family, and friends in a difficult position of deciding how to care for an individual. Additionally, considering the health

disparities faced by LGB older adults (Fredriksen-Goldsen et al., 2013), planning about healthcare needs is essential to help mitigate cumulative disadvantages affecting this population.

Yet, scant research has examined how LGB older adults are planning and making decisions about healthcare and end-of-life arrangements (Cartwright, Hughes and Lienert, 2012; Czaja et al., 2015; Stein and Bonuck, 2001). Despite the 2015 decision by the Supreme Court to legalize same-sex marriage across the U.S., older LGB adults still face discrimination and other barriers to having their end-of-life wishes respected, and same-sex marriage laws do not address the situations of those who choose not to marry or are not partnered. Existing studies of advance care and end-of-life planning among LGB people, which have tended to sample wealthy, highly educated adults *under* age 60, indicate that: (a) race and ethnicity (Stein and Bonuck, 2001) as well as relationship status (de Vries, Mason, Quam, et al., 2009) are associated with degree of planning efforts, and (b) LGB adults express concern about who might care for them in older age (Hash, 2006). De Vries and colleagues (2009) analyzed data from a 2006 nationwide online survey of 793 LGB Baby Boomers who were between the ages of 40 and 61. Fewer than half had either a will (48.4%), living will (48.3%), or healthcare durable power of attorney (45.7%; de Vries et al., 2009). Those who lived in a state that did not recognize same-sex relationships at the time of the survey were more likely to have preparations in place. Additionally, those who were currently partnered were also significantly more likely to have such plans in place; thus, relationship status may be a key factor in planning.

As part of the first federally-funded national study of lesbian, gay, bisexual and transgender (LGBT) aging, a survey was conducted with over 2,500 adults ages 50 to 95 through community-based organizations across the U.S. (Fredriksen-Goldsen et al., 2011). In contrast to findings of de Vries and colleagues' 2009 study, this survey indicated that 70% of these adults

had a will in place and 64% had a durable healthcare power of attorney (Fredriksen-Goldsen et al., 2011). The higher rates of late life planning in this study could be because this was a much older sample than the study by de Vries and colleagues. However, it could also be related to how Fredriksen-Goldsen and colleagues recruited LGBT adults through community agencies; adults active in such organizations may be more likely to plan for late life needs as a function of greater levels of initiative, health literacy, and/or community engagement.

### **Conceptual Framework**

The Health Equity Promotion Model (Fredriksen-Goldsen, Simoni, et al., 2014) is a recently proposed framework that is meant to examine factors influencing LGB and transgender health disparities across the life course. This model suggests that health is influenced by the context of one's life (individual and structural factors, such as social stigma or abuse) as well as a person's social positions (intersectionality) and particular pathways that can promote or hurt one's health throughout life. These pathways can be behavioral (e.g., preventative care), social and community-related (e.g., social support), psychological (e.g., internalized homophobia), or biological (e.g., the body's reaction to chronic stress). Advance care and end-of-life planning are specific behaviors that evidence suggests can promote quality of death and ensure healthcare treatment preferences are respected in later life (Detering et al., 2010); thus, encouraging adults – particularly populations that face health disparities in later life, such as LGB adults – to engage in these behaviors can be an important goal for service providers who wish to support this population and ensure the best care possible in later life.

### **Research Question**

Our research question is: What motivates LGB older adults to make advance planning decisions regarding future healthcare and end-of-life wishes?

## Methods

In this exploratory study, we used a semi-structured interview guide to conduct in-depth interviews with adults aged 65 and older who identified as gay, lesbian, bisexual, or same-gender-loving and lived in a metropolitan area in the Southeastern U.S. We approached recruitment by sharing announcements of the study with local organizations that serve lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ) populations, as well as LGBTQ-affirming faith communities and medical offices and pharmacies serving large LGBTQ populations in a large city. We also reached out to key gatekeepers among LGBTQ communities of color and asked for their assistance in broadcasting information about the project on social media sites. Announcements about the study stated the project's focus, the qualifications for participation, and that \$10 remuneration would be provided to participants. Our study's methods were approved by the IRB at Georgia State University. Through an iterative process of interviewing and then purposively sampling for maximum variation, nine participants were recruited until data reached a point of saturation and there was replication of themes across participants.

Potential participants contacted the first author, who then screened each person to determine eligibility (i.e., aged 65 or older, identified as LGB or same-gender-loving, and lived in the metropolitan region of the study). We chose this age group because most studies of LGB adults and advance care and end-of-life planning tend to focus more on middle aged adults, and we were specifically interested in the behaviors of LGB older adults, who may already be facing significant health challenges. We focused on one metropolitan area in the Southeastern U.S. both due to an interest in understanding LGB adults in a region where they tend to face heightened stigma and due to resource limitations to expanding data collection to multiple regions. Those



who qualified were told that the study entailed a face-to-face interview of about 1-2 hours about decisions regarding healthcare needs and aging-related care, followed by a brief pen-and-paper survey to collect demographic data, involvement in LGBTQ organizations, religiosity, and social support. Although not explicitly stated in recruitment materials, our semi-structured interview protocol included questions on end-of-life wishes and planning, as this was a planned topic of inquiry within the larger study. Participants chose a location for the interview that allowed for comfortable conversation about sensitive topics. Interviews were conducted by the first or fourth author. Afterwards, a graduate research assistant transcribed the interviews. We removed all identifying information from the interview data during the process of transcription.

### **Data Analysis**

Our research team conducted qualitative content analysis (Patton, 2002) of the interview data, based on our research question of interest. Our stages of content analysis align with those described by Bengtsson (2016), including *Decontextualization, Recontextualization, Categorization, and Compilation*. As part of the Decontextualization Stage, we repeatedly listened to the recorded interviews and read transcripts individually, then began identifying “meaning units” within the data, labeling these meaning units with inductive open codes. As a team, we met to discuss and come to agreement on code definitions and labels, deciding which content to include and which could be excluded (Recontextualization Stage). During this process, we modified some code labels and deleted others until we shared an agreed upon list of codes. As additional interviews were added to the dataset, we continued the process, often adding new codes and modifying others to capture new concepts and ideas. Next, we further organized and clustered codes into sensible categories based on codes that appeared related (Categorization Stage). With preliminary categories identified, we made adjustments until all relevant data were

captured within a category. As our final stage (Compilation), we reviewed participants' words within each category to verify our understanding of the categorization and determine a succinct description of that theme, discussing these results and comparing findings with what is documented in the literature (Bengtsson, 2016).

To enhance trustworthiness, we recruited a diverse set of participants until reaching thematic saturation. Both interviewers are members of the LGB community and were trained in sensitively inquiring about end-of-life topics. We used a semi-structured interview guide to maintain focus on the topic of interest, while allowing flexibility to explore different respondent realities. We also maintained an audit trail (Suter, 2009) including writing analytic memos during data collection and analysis. While transcribing interviews, we conducted an audibility check- a second person on the team listened to recorded interviews and compared to the transcription, making corrections as appropriate (Suter, 2009). We bracketed researcher ideas and biases in analytic memos that were shared during peer-debriefing at each phase of the study.

## **Findings**

### **Participants**

Nine participating adults ranged in age from 65 to 77, with a median age of 72. Five participants were cisgender (non-transgender) men, while the remaining four participants were cisgender women. Six individuals were white/Caucasian, while three were African American/Black. Five were currently partnered, while four were single. Five participants were parents, all from previous heterosexual relationships. Monthly individual income, including Social Security, ranged from \$945 to \$5,000/month, with a median of \$1,800/month. The sample was highly educated, with six participants having a graduate degree. Seven of the nine participants lived in a suburb of a large city, while two lived in a large city. All participants were

asked during the interviews whether they currently had advance care directives (healthcare power of attorney and living will). Five participants indicated that they had an advance directive; the remaining four participants did not have an advance directive. See Table 1 for a list of details for each of the nine participants, including whether they had an advance directive.

### **Motivations for Advance Care Planning**

We identified three themes that motivate advance care planning among this sample: wanting a sense of agency, learning from others, and reducing conflict and confusion for loved ones.

**Wanting a sense of agency.** Participants who engaged in advance care planning expressed the importance of having a say about their caregiving and end-of-life arrangements. Their words reflected a sense of agency – desiring and enacting influence on caregiving, health-related decisions, and end-of-life care and arrangements. They thus took steps to make decisions, discuss options, and document preferences through legal documents as well as through informal conversations with loved ones. For Joni,<sup>1</sup> a 77-year-old single white woman, making plans just seemed to make sense: “I better do it, because I knew there were some things that I wanted, some things that I didn’t want, and the only way that could be guaranteed was to write it down.” She was a unique participant in that her family openly discussed medical issues when she was growing up. Consequently, by age 40, she already had a living will and plans in place for her body’s care upon her death:

Every year on January 1<sup>st</sup>, I look at [my living will] and see if I want to make changes.

It’s changed over time. I have decided my body’s going to the Body Farm in Tennessee.

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<sup>1</sup> We use pseudonyms in this article to maintain the confidentiality of participants.

It is a research facility where they put cadavers out into the field, and every day they track what Mother Nature's doing.

Joni became aware of the work of photographer Sally Mann, author of a project titled *What Remains* in which cadavers are memorialized on film. Joni expressed that although it was difficult to look at these bodies, she found the images to be beautiful. So, she adopted this "great idea" and informed her brother of her decision:

I said to him, "This is what I'm thinking about doing. How do you feel?" because I didn't think he should be blindsided. He said, "Well, whatever you want." And I said, "Okay, I don't need your approval, but I just want you to know that's what's going to happen.

Joni's narrative placed great emphasis on being able to make her own decisions about the end of life. She discussed a preference for the treatment of her body that reflected her values.

Other participants also described a need for agency, whether in connection to wishes for healthcare treatment or remembrance after death. Paul, a white, 70-year-old partnered gay man, first established an advance directive in his early 50s after the loss of a previous partner:

After his death, I realized that I needed to take care of myself, and I was alone in the world, and so at that point, I was in my early 50s, and I took care of all of these things. I got a will, I gave my sister power of attorney, and all sorts of things like that. I took care of all of those documents at that point. Just recently, within the last 2 or 3 years, [this state] has changed from what they called durable power of attorney for health care, and they changed it now to [State] Advanced Directive... So when they changed that, I didn't immediately make the switch, but then [my current partner and I] got into a conversation about six months ago about what happens if one of us is in the hospital, could the other

come to visit, for instance? So we both decided now we really ought to, in light of our relationship, redo those documents.

**Learning from others.** Secondly, participants described learning about the importance of putting advance care plans in place from professionals and loved ones. Some were warned about possible negative outcomes of not having plans in place, while others witnessed difficult situations among loved ones firsthand that taught them the importance of advance care planning.

**Learning from professionals.** Joni asserted that she has primarily received information about advance directives from attorneys. A dear lawyer friend helped her get started and “[took] care of it all.” The idea of professionals being at the forefront of disseminating advance planning information was supported by Bette, a 65-year-old white woman. Although she was approached during a doctor’s appointment with an ex-girlfriend about creating an advance directive, Bette already had documents in place at the time. More recently, after starting a relationship with her wife, Bette recalled a serendipitous encounter with lawyers who were distributing information about advance directives at a Pride event:

The guys next to us were lawyers ...And then [my wife] had run into somebody in the gay network, an attorney...We just thought that we needed to do it. Especially for health care... And a lot of it comes from attorneys, not necessarily people in health care. I think attorneys were the first people to really talk about living wills...

Other participants also reported getting information from professionals, including Johnny, a partnered 74-year-old white man who took a course on advance directives from the local Osher Lifelong Learning Institute: “I took a course at [local university], and that was the first I saw that [advance care] directive. [They have] very reasonable tuitions, all sort of subjects. So, they had somebody come give a class on [advance care] planning.” Another participant, Paul,

gathered information from a local nonprofit organization that educates people about planning for the end of life. As a result of engagement with his group, Paul made firm plans for his cremation after death. He described:

[The organization] doesn't just advocate cremation, but that's one of their big pushes.

They also try to get people to write down what they want and do these documents. I joined them about ten or fifteen years ago. You choose a particular funeral home. I chose one that does cremation, and I set things up so that I would be cremated. Then, as far as other documents related to being incapacitated and things like that, they'll help you with that, too.

*Learning from loved ones.* Witnessing illness and experiencing the loss of family members and friends sometimes made participants aware of the need for advance directives or reinforced earlier decisions to have them. Bette recalls:

Yeah, my brother was gay, and he died from AIDS in the 1980s. He didn't have a partner or anything, but it just got me to thinking about [advance care planning]. And then, my ex-husband's nephew died when he was, I think he was like 22 or something... very young. We were in [a different Southeastern state], and they didn't want to let his partner in. It was just a nightmare.

Such experience influenced Bette's own approach to planning. Similarly, as mentioned earlier, when Paul's previous partner died, he already had a living will, but the death helped him realize the need to take action for himself by setting up his will and durable health care power of attorney.

Joni's openness to talking about death, dying, and planning for the end of life emanated from her parents' examples. Joni's father died young, and her mother, a nurse, was sure to

discuss what she wanted to happen for her at end of life. Joni recalled conversations about death being normal, “just a part of life.” She remembers the effects of the AIDS epidemic and how the deaths of people she was close to, including a woman with AIDS who she supported as a volunteer, made her acutely aware of the need for putting plans in place. Joni established her advance directive in the mid-1980s, but multiple deaths reinforced her decision to be certain plans “were taken care of in the way that I wanted it to be done.” She recalled:

Those days, everybody was dying. I lost a lot of people. I lost a lot of my neighbors. I mean, in early '84, [AIDS] was a death sentence then...So maybe that led to thinking more about it, and I had a buddy, young woman ...and I got to be with her when she died. So, I think that whole journey reinforced [why I should engage in planning].

Judy, a 72-year-old Black lesbian, was also motivated to put legal plans in place by witnessing family members' deaths:

Prior to moving to [this state] five years ago, my mother had an extended diagnosis with Alzheimer's and was unable to care for herself, so the family was primarily providing services and making medical decisions for her. So, I got involved in that at some point. [Interviewer: So that made you think about those things?] Right. And my daughter-in-law's mother was ill, and she was involved [from here], and her mother was in [another state], so she was involved with the family in making decisions, going up signing papers and doing all those kinds of things.

This early exposure to the complications of making healthcare decisions prompted Judy to consider making plans for herself.

**Reducing conflict and confusion for loved ones.** Participants also spoke to the importance of reducing potential conflict and confusion for loved ones as a motivation for

advance care planning. For example, James, a single gay man who was 65 years old, stated, "It's bad when you don't know what a person wants and when you don't have written things out to do. I've seen that happen to other families. Well, we don't want this to happen to us." He recalled, "Even with my mother, she had been sick back and forth for about a year. About six months before [her death], she just kinda gave up on just everything, and she wanted us to put everything together." James' mother was in her 50s when she passed way; he remembers his planning conversations with his mom as "the hardest thing" and wondered, "Why are we talking about this now?!" He was 40 years old at the time and felt they should be discussing her health recovery. His mother clearly stated, "I'm not getting any better. This is what it is. We need to talk about this and get this done now." Reflecting on this memory, James explained that he would not want his siblings to go through a similar situation, so while he is "alive and doing everything lively," he is having these difficult conversations with his family, although has yet to put them in writing.

Bette is also having conversations with loved ones about her needs later in life, particularly in terms of where she might live if her health severely declines; she has an awareness of not "want[ing] to be a burden" to her children, particularly if she develops a condition like Parkinson's disease or Alzheimer's disease, both conditions she has seen family members develop. She has been comforted by her youngest child's saying, "Well, mom, I always thought that you would come live with me if you needed to." This agreement was both in line with her own wishes but also helped clarify plans among members of Bette's family.

In sum, respondents identified three motivations for putting advance directives in place: (1) wanting a sense of agency regarding healthcare, caregiving, and end-of-life arrangements, (2) learning about the benefits of advance directives from professionals and from family and friends'



own experiences with aging and death, and (3) reducing conflict and confusion among loved ones who must make difficult decisions in the event of one's illness, incapacitation, or death. Such motivations are not necessarily unique to LGB adults but may be particularly salient for discussion with this population, given their health risks, likelihood of encountering homophobia/biphobia in healthcare and aging services, and greater chance of disconnection from their family of origin.

### **Discussion**

This study explored motivations of LGB older adults when making decisions about future healthcare needs, implementing advanced directives, and planning for the end of life. Our interviews with nine participants documented three themes related to motivations of planning behaviors: wanting a sense of agency, learning from others, and reducing conflict and confusion for loved ones. Among those who engaged in planning, some spoke about wanting to determine what their healthcare and end-of-life arrangements would look like. This desire for agency was one of the major drivers of advance care planning, which mirrors findings from studies of general populations of older adults (Carr, 2012; Levi, Dellasega, Whitehead et al., 2010). Being able to exert control over healthcare treatment and end-of-life arrangements may be particularly important for some LGB older adults, especially when so much of their lives and their intimate relationships may be invisible or subject to discrimination by their families of origin and/or healthcare providers (Fredriksen-Goldsen et al., 2011; Orel, 2014). Social workers and gerontologists can help such clients frame advance care planning as a means of "having a say" in their healthcare and end-of-life arrangements by putting their wishes in writing. In the education of future social workers and professionals, this drive for agency can be integrated into case studies related to advance care planning for hypothetical clients and connected to practitioners'

commitment to honoring client self-determination, which is one of the ethical standards contained within the NASW Code of Ethics (2017).

A second motivator for engaging in planning was based on what LGB adults learned from other people—whether from professionals knowledgeable about advance care planning or through witnessing a loved one get sick or die while others had to make decisions on their behalf. A number of participants spoke of learning about advance care plans from either legal professionals, medical providers, or nonprofit staff who specialized in providing information to seniors; past research suggests that seniors who have accrued knowledge about advance care planning are also more likely to engage in planning themselves (Fried et al., 2010). Although Bette mentioned being prompted to update her advance directive after talking with lawyers at a Pride event, most participants did not speak to any LGBTQ-specific events that distributed information about advance care planning. This finding emphasizes that information about planning may best be distributed through a variety of outlets to reach this population, including general healthcare providers, senior services professionals, and others who regularly interact with older adults. However, it's important that outreach happening in such settings is attuned to the cultural needs and sensitivities of LGB seniors to effectively serve this population (Erdley, Anklam and Reardon, 2014; Fredriksen-Goldsen, Hoy-Ellis, Goldsen, et al., 2014). Our findings may also indicate that LGBTQ organizations simply are not reaching seniors with information about advance care planning and that additional outreach would be helpful. Similarly, this finding emphasizes the importance in educating future providers for sensitively anticipating and responding to the needs of LGB seniors, whether or not they specifically intend to practice with LGBTQ populations. Social workers and others can play a role in helping to provide clients with

information about what advance care and end-of-life planning are and the benefits these strategies can offer to individuals and their families.

Additionally, participants' planning behaviors were greatly influenced by witnessing the health situations of friends or loved ones. Some of those interviewed had friends or family members who died while very young, and this reinforced how vulnerable each person is and how serious illness or death can happen unexpectedly. Previous research has found that when older adults have had to make medical decisions for someone close to death, they are more likely to talk with loved ones about their own values regarding quality versus quantity of life (Fried et al., 2010). Additionally, other studies have highlighted the power of direct caregiving experiences, hearing the caregiving stories of others, witnessing a loved one's end-of-life care or painful death, and having to make medical decisions for others as prompts for advance care planning among middle age and older adults (Carr and Khodyakov, 2007; Carr, 2012; Levi et al., 2010).

Relatedly, participants said they were motivated to engage in planning due to a desire to minimize conflict among family members upon a change in one's health, particularly in situations where there is family strain or when an intimate relationship is not respected by all parties. Some participants who were single and without children similarly expressed a wish not to be a burden to relatives, such as nieces and nephews, who may already be parenting or caregiving for others. Past research with general groups of middle age and older adults has similarly highlighted how concerns about not being a burden on others can influence advance care planning (Carr, 2012; Levi et al., 2010). Participants who engaged in advance planning reflected on the impact that a change in their health could have on their partners, family, and friends. Social workers can be mindful of how such social factors influence advance care planning; even if a client has not witnessed the death of a loved one, professionals might prompt

reflection among clients by sharing sample written scenarios of people facing unexpected health conditions that impact decision-making capacity and the dilemmas such situations present for families and for the individual. These scenarios may be helpful in prompting further reflection and discussion among social service providers and their clients that can lead to engagement in advance care planning among LGB seniors.

### **Limitations**

While our study had a number of strengths, such as targeted outreach to single LGB adults and communities of color and the use of in-depth interviews to understand motivations for advance care planning, there were also limitations to our methods. Our findings drew upon the experiences of a small, highly educated sample of LGB seniors. Thus, findings should not be generalized to all LGB seniors. Second, we only targeted seniors in one city in the Southeastern U.S., and all participants were either White or African American; future studies might explore whether similar patterns occur among LGB seniors in other regions of the U.S., in rural areas, who are lower income, and who have other racial or ethnic identities. Our recruitment methods particularly targeted individuals based on identification as a LGB or same-gender-loving because we were interested in studying advance planning among this population; we left open the possibility that one or more participants might also be transgender, but this did not materialize. Transgender older adults deserve further attention in research, including in studies of advance care planning. Future studies could target larger samples of LGB older adults to test quantitative relationships between social and demographic factors and engagement in advance care planning. Finally, there is a need for longitudinal research that can examine how planning behaviors of LGB adults emerge and change across adulthood and in relationship to major life events, such as being diagnosed with a chronic condition.

### **Conclusion**

This study used in-depth interviews with nine LGB older adults in the Southeastern U.S. to explore motivations for engaging in advance care and end-of-life planning. By understanding the motivations that may drive planning behaviors, social workers and other helping professionals working with older LGB adults can improve how they frame conversations about initiating advance care directives with this population. Ultimately, by encouraging planning among LGB older adults, the hope is that we can better respect the wishes of LGB older adults regarding health care treatment, caregiving, and end-of-life care and arrangements and improve their experience of aging.

## References

- Bengtsson M (2016) How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, 2, 8-14. DOI: 10.1016/j.npls.2016.01.001
- Boehmer U, Clark M and Sullivan M (2010) Advance care planning by unmarried women of different sexual orientations: The importance of social support. *Journal of Women & Aging* 22(4): 306–20. DOI: 10.1080/08952841.2010.518884
- Carr D (2012) “I don’t want to die like that ...”: The impact of significant others’ death quality on advance care planning. *The Gerontologist* 52(6): 770–781. DOI: 10.1093/geront/gns051
- Carr D and Khodyakov D (2007) End-of-life health care planning among young-old adults: An assessment of psychosocial influences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 62(2): S135–S141. DOI: 10.1093/geronb/62.2.S135
- Cartwright C, Hughes M and Lienert T (2012) End-of-life care for gay, lesbian, bisexual and transgender people. *Culture, Health & Sexuality*, 14(5): 537–48. DOI: 10.1080/13691058.2012.673639
- Czaja SJ, Sabbag S, Lee CC et al. (2015) Concerns about aging and caregiving among middle-aged and older lesbian and gay adults. *Aging & Mental Health*, 7863: 1–12. DOI: 10.1080/13607863.2015.1072795
- de Vries B, Mason AM, Quam J, et al. (2009) State recognition of same-sex relationships and preparations for end of life among lesbian and gay boomers. *Sexuality Research & Social Policy*, 6(1): 90–101. DOI: 10.1007/BF03165990
- Detering KM, Hancock AD and Michael C (2010) The impact of advance care planning on end

- of life care in elderly patients: Randomised controlled trial. *BMJ*, 340: 1–9. DOI: 10.1136/bmj.c1345
- Erdley SD, Ankam DD and Reardon CC (2014) Breaking barriers and building bridges: Understanding the pervasive needs of older LGBT adults and the value of social work in health care. *Journal of Gerontological Social Work*, 57(2–4): 362–85. DOI: 10.1080/01634372.2013.871381
- Fredriksen-Goldsen KI, Hoy-Ellis CP, Goldsen J et al. (2014) Creating a vision for the future: Key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services. *Journal of Gerontological Social Work*, 57(2-4): 80-107. DOI: 10.1080/01634372.2014.890690
- Fredriksen-Goldsen KI, Kim HJ, Barkan SE et al. (2013) Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study. *American Journal of Public Health*, 103(10): 1802–9. DOI: 10.2105/AJPH.2012.301110
- Fredriksen-Goldsen KI, Kim H, Emler CA et al. (2011) The Aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults. Report. Available at: <http://age-pride.org> (accessed 3 September 2015).
- Fredriksen-Goldsen KI, Simoni JM, Kim HJ et al. (2014) The health equity promotion model: Reconceptualization of lesbian, gay, bisexual, and transgender (LGBT) health disparities. *The American Journal of Orthopsychiatry*, 84(6): 653–63. DOI: 10.1037/ort0000030
- Fried TR, Redding CA, Robbins ML et al. (2010). Stages of change for the component behaviors of advance care planning. *Journal of the American Geriatrics Society*, 58(12): 2329–2336. DOI: 10.1111/j.1532-5415.2010.03184.x
- Gates GJ (2011) Family formation and raising children among same-sex couples. National

- Council on Family Relations: Family focus on LGBT families, pp. F1–F4. Available at: <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-Badgett-NCFR-LGBT-Families-December-2011.pdf> (accessed 26 July 2016).
- Hash K (2006) Caregiving and post-caregiving experiences of midlife and older gay men and lesbians. *Journal of Gerontological Social Work*, 47(3/4): 121–138. DOI: 10.1300/J083v47n03\_08
- Kass-Bartelmes BL, and Hughes R (2004) Advance care planning: Preferences for care at the end of life. *Journal of Pain & Palliative Care Pharmacotherapy*, 18(1): 87–109. DOI: 10.1300/J354v18n01\_08
- Levi BH, Dellasega C, Whitehead M et al. (2010). What influences individuals to engage in advance care planning? *American Journal of Hospice and Palliative Medicine*, 27(5): 306–312. doi: 10.1177/1049909109355280
- Muraco A and Fredriksen-Goldsen K (2011) “That’s what friends do”: Informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults. *Journal of Social and Personal Relationships*, 28(8): 1073–1092. DOI: 10.1177/0265407511402419
- National Association of Social Workers (2017) *Code of Ethics of the National Association of Social Workers*. Available at: <https://www.socialworkers.org> (accessed 7 March 2018).
- Orel NA (2014) Investigating the needs and concerns of lesbian, gay, bisexual, and transgender older adults: The use of qualitative and quantitative methodology. *Journal of Homosexuality*, 61(1): 53–78. DOI: 10.1016/j.micinf.2011.07.011.Innate
- Patton M (2002) *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Seelman KL (2018) Differences in mental, cognitive, and functional health by sexual orientation



among older women: Analysis of the 2015 Behavioral Risk Factor Surveillance System.

[Advance online publication] *The Gerontologist*. doi: 10.1093/geront/gnx215

Stein GL and Bonuck KA (2001) Attitudes on end-of-life care and advance care planning in the

lesbian and gay community. *Journal of Palliative Medicine*, 4(2): 173–90. DOI:

10.1089/109662101750290218

Suter E (2009) Validity in qualitative research on personal relationships. *Kentucky Journal of*

*Communication*, 28(2): 77-96.

Table 1.

*Descriptive Information about Research Participants*

Pseudonym	Age	Race	Relationship Status	Degree of being "out"	Advance Directive?
Bette	65	White/Caucasian	Partnered	Everyone	Yes
James	65	African American/Black	Single	Most people in social network	No
David	67	White/Caucasian	Single	Everyone	No
Paul	70	White/Caucasian	Partnered	Most people in social network	Yes
Judy	72	African American/Black	Partnered	Most people in social network	Yes
Bob	74	White/Caucasian	Single	A few close friends/family	No
Johnny	74	White/Caucasian	Partnered	Most people in social network	Yes
Ella	75	African American/Black	Partnered	A few close friends/family	No
Joni	77	White/Caucasian	Single	Most people in social network	Yes