

End-of-Life Care Perceptions and Preparations of Lesbian, Gay, Bisexual, and Transgender Older Adults



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Background

There are currently 2.7 million individuals 50 years old and older who identify as lesbian, gay, bisexual, or transgender (LGBT). By 2030, the LGBT older adult population will more than double to 7 million. Being less likely to have children, more likely to live alone, and more likely to experience their circle of support become smaller, LGBT older adults may have to rely on themselves for end-of-life care planning. Though the supreme court granted marriage equality in 2015, there is still a lack of protective legislation. Currently in the state of Missouri there are no employment, public accommodations, or housing protections for LGBT individuals. With the lack of legal protection, a lifetime of discrimination and stigma, and being less likely to access services, Older LGBT adults must take measures to ensure their end-of-life wishes are respected.

Research Questions

1. What are LGBT older adults' perceptions of end-of-life care?
2. Do LGBT older adults think and plan for their end-of-life care?
3. What are the concerns and challenges for LGBT older adults as they work toward their "ideal" end-of-life care experience?

Methods

- Grounded Theory Methodology
- Snowball sampling through community partners
- Semi-structured interview schedule

Interview Protocol Themes & Examples

Awareness

- Have you ever thought about your end-of-life care?

Goal Setting

- What do you want to happen when it's your time to "go"?

Perception and Feasibility of End-of-Life Care Goals

- Do you think you will have this ideal end-of-life experience? Why or why not?

Preparation

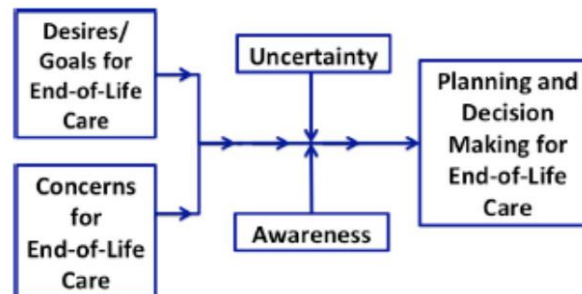
- Have you shared your end-of-life care wishes with loved ones? Why/why not? With your physician? Why/why not?

Results

Sample Characteristics (N=17)

Age	Mean 69.59 years; Range: 61-81; SD=±6.58
Gender Identity	29.41% female 58.82% male 11.77% non-binary (neither male or female)
Race	100% white
Sexual Orientation	82.35% gay or lesbian 5.88% bisexual 11.76% other
Relationship Status	17.65% legally married 35.39% partnered 47.05% single

Model of End-of-Life Planning and Decision Making



Main Themes

Desires and Goals for End-of-Life Care

- Recognition of "Family of Choice"
- Be Seen as "True Self," Being "Out"

"I decided, I wish more years ago than I care to admit, I just decided no I will not lie [referring to her lesbian identity]. I'm not gonna hide anything because that diminishes one's feeling of self." 81 y.o. lesbian woman

Concerns for End-of-Life Care

- Not wanting to be a burden

"I would kind of rather be in a facility, not have other people have to deal with me." 64 y.o. lesbian woman

- Cost of care

Uncertainty

- Fear of institutionalized care as LGBT

"You can never trust [institutionalized care], and you certainly can't trust the Catholic place." 74 y.o. gay man.

- Timeframe

Awareness

- Prior experience as reference
- Knowledge of legal documents and protections

"I know that I need to go meet with someone and write some of this stuff down because I don't have a living will...it's just something that you are like, 'oh yeah, I need to do that.'" 61 y.o. queer non-binary person

Discussion and Implications

- Multiple factors related to end-of-life planning
- Sample mostly prepared but uncertain
- Desire to have LGBT identity recognized and respected
- However, fear of institutionalized care due to LGBT identity

Older LGBT adults have their own unique desires and concerns for end-of-life care (e.g. being "out"). In addition, they share similar concerns with non-LGBT older adults (e.g. concern about cost of care). With older LGBT adults less likely to have children, partners, or family of origin to care for them, aging service providers must educate this population about end-of-life care planning, stress the importance of legal documentation, as well as provide a welcoming environment.