LGBT individuals and end-of-life preparation: Reflections from the Nova Scotia context

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Dr. Áine M. Humble, Sarah Paterson (MA student)
Department of Family Studies and Gerontology, Mount Saint Vincent University
Dr. Jacqueline Gahagan, Kirk Furlotte (MA Student)
School of Health and Human Performance, Dalhousie University

TVN Improving care for the frail elderly

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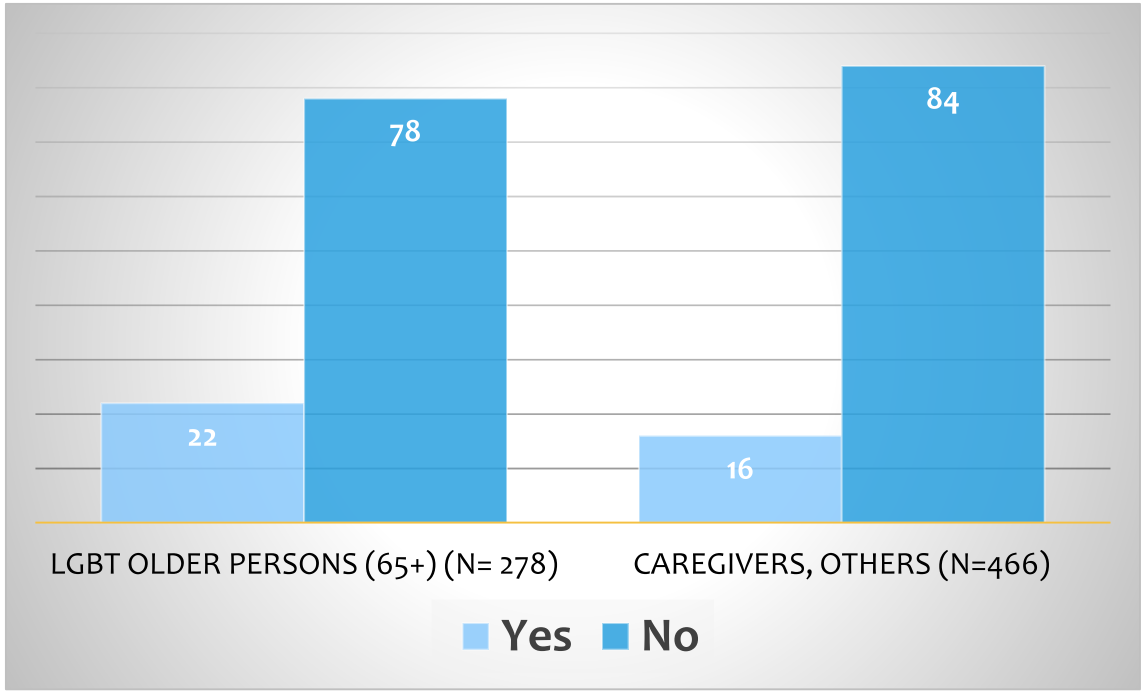
Overview

1. Introduction
   - Definitions
2. Sample- who did we talk to?
3. Findings from local focus groups
4. The inventory
5. Experiential exercise
6. Questions

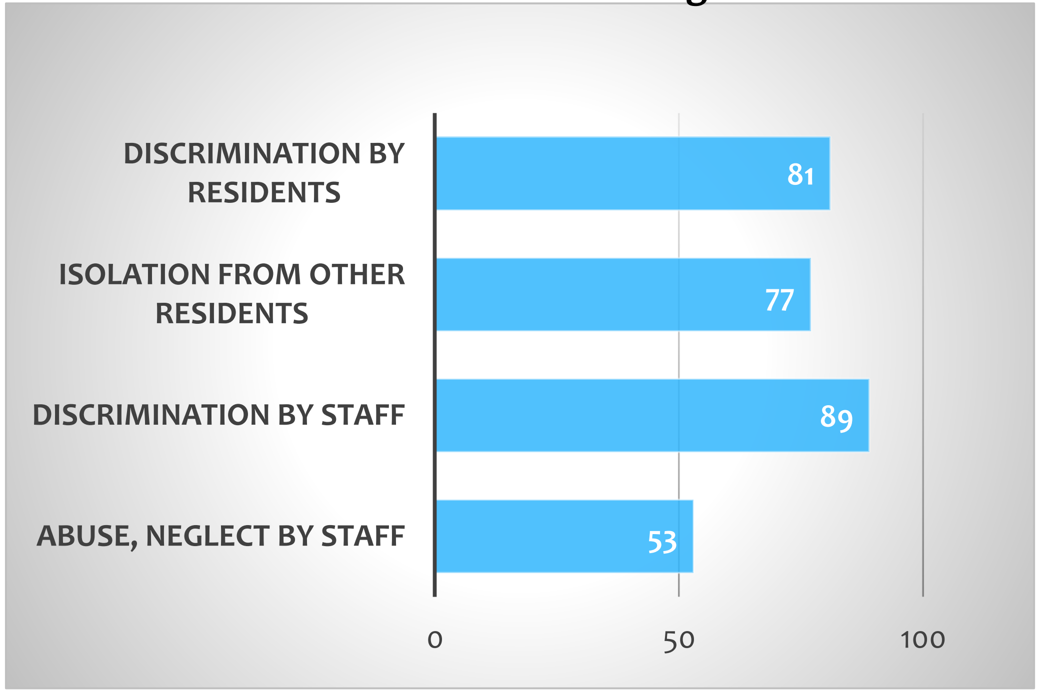
LGBT Persons in Long-Term Care Settings

(Source: SAGE (2011). LGBT older adults in long-term care facilities.)

Can LGBT older persons be "out" in LTC setting?



Fears/ expectations of LGBT older persons in LTC settings:



Sexual Orientation and Gender Identity

- Sexual Orientation
- LGB
- Heterosexual
- Heterosexism
- Homophobia/biphobia

- Gender Identity
- Transgender
- Cisgender
- Cisnormativity
- Transphobia

Who were the people we spoke with?

- Four focus groups:
  - Bisexual and gay men- 8
  - Bisexual women and lesbians- 6
  - Transgender individuals- 2
  - Service providers- 4

- Average age of LGBT participants: 67
  - Youngest- 59
  - Oldest- 82

LGBT Participants

- Relationships
  - Status
  - Relationship Duration
  - Children
  - Extent of Being “Out”
  - Number of Close Friends
- Living Arrangements
- Education
- End-of-Life Preparation
  - Primary Caregiver
  - Legal Documentation
- Chronic Conditions
- Level of Comfort with Technology

Service Providers

- Sexual Orientation
- Gender
- Education
  - Professional Training
  - Specialized Training in Aging
  - Specialized Training for LGBT Clients
- Duration of Work in the Field
- Proportion of LGBT Clients

Theme 1: Communities of Care

- How we care for ourselves and/or each other as we age emerged as an important theme.
- The changing landscape of communities of care was tied in with a lack of unifying cause or issue.
- Who we care for and the type of care yields a certain configuration of ‘communities of care’, which may not be related to families of origin.

Theme 1 (cont.)

- Shifting from the urgency of health crises such as HIV experienced within the LGBTQ communities.
- Lack of perceived urgency or flashpoint to mobilize aging LGBTQ communities.
- Reshaping communities of care to those in need (elderly neighbour, injured acquaintance)
- Reluctance to seek or request care from others (paid or unpaid).
- Not wanting to be a burden, not wanting to have to challenge issues related to being LGBTQ

Theme 1: Quotes

"…approaching 70 seems to be definitely time to think about it and…like I said I think it's the isolation that I fear, the dependence on 1 person is probably, well I wouldn't say it's the same as not having any person, but it's very limited, like the support I can expect."

"…like when you're down or something, can you pick up the phone and call somebody and neither of these people would I call in that kind of thing…"

"…I think my one sister…she might come [to provide care] *for a little while…"*

Theme 1: Quotes (cont.)

“And it is not down in black and white, then you go through the pecking order of who makes decisions and it may not be the person that you want.”

“It’s an interesting door into the idea of how are we going to take care of each other.... ”

“…when I began working in HIV/AIDS it was just before the really strong antiretrovirals came in…and I really witnessed levels of care, community care teams, working together. People from the community mobilizing…Gay men and lesbians coming together to care for people from their community… I’ve seen less and less of that…”

Theme 2: Difficulty Asking People for Assistance

- What it is like to reach out to others if you need assistance or if you *might* need assistance?
- Personal
  - **Activities of Daily Living**: basic self-care tasks, such as eating, bathing, dressing, toileting, continence, and getting up and down from a chair
- Functional
  - **Instrumental Activities of Daily Living**: cooking, driving, using the computer, shopping, legal document preparation, medication management, housekeeping
- Emotional

Theme 2: (cont.)

- Not wanting to be a burden on others
  - Emotionally
  - Physically
  - Financially
- Isolation
- Afraid of the kind of care one will get (heterosexism and homophobia)
- Later-life friendships different

Theme 2: Quotes

“I’m not going to certainly ask my family to look after me. I have my sons here but I would not do that.”

“Women might be more hesitant to ask other women to help us because we understand the financial inequalities.”

“I am single, no children, no terribly close family so it’s kind of a ‘what do you do in that case?’”

“I attended a visitation for a gay man that died last week. And I got there at 4:30. It started at 3 o’clock and, at that point, 12 people had signed in. Which I thought, ‘Holy mackerel, I hope some people show up after work.” Otherwise, this man was alone’.”

Theme 2: Quotes (cont.)

“If you’re isolated or you don’t have a strong support network. Or you’re very distrustful, which we know, and literature shows us, that LGBTIQ folks tend to have much less trust of healthcare. Whether it’s home care or whatever it is, healthcare in general, if you don’t trust that system, why would you want them in your home?”

“I talked to a supervisor and told her I was transgender. I said, ‘Theoretically, my breasts are relatively young.’ She couldn’t tell me whether or not I really needed [the mammogram] *or not, because I don’t follow the normal criteria of a woman my age.”*

“I can’t imagine myself kind of looking for people that are going to be friends so that they can look after me?”

Theme 3: Hesitancy to Think About End-of-life Issues

- In the past, many rallied around their friends and lovers to help them (HIV/AIDS)
- Today, there is a general fearfulness about talking about death and dying
- This can lead people to delay making important preparations
- Preparations (e.g., wills) may also need to be revisited on a regular basis

Theme 3: (cont.)

- Being a caregiver to someone else
- Relationship status—may think more about it if have a partner
- Few people to have discussions with
- Fear of end-of-life
- Something far away in the distance
- Concerns about care- heteronormativity and homophobia
- Health issues can make it difficult to talk about end-of-life
  - Physical
  - Mental
- Socioeconomic status and education level

Theme 3: Quotes

“Maybe part of it is that I just had way more things in place when I had a partner. Because I cared.”

I just don’t have anybody to talk to like that’s the isolation that I have described.”

“There’s tons of fear around it. . . I have no plan.”

“I’d like to think that end-of-life is fairly far away for me.”

“I have to pay more attention to this kind of stuff and at times I would like to have a check list.”

Theme 3: Quotes (cont.)

“I think the dying issue is somewhat similar to the gay issue, you know, most gays are becoming more and more out. And they’re out of the closet and more open and so on. And I think dying and end-of-life issues are still are still kept underground a lot.”

“You can’t assume that care providers are going to take the relationship, your relationship that you identify as important, partnerships, seriously.”

“Something else is how comfortable they are discussing their health, which many people aren’t. And possibly if there’s an HIV diagnosis or something else that potentially is also related to the healthcare that they’d be comfortable—discussing that with other people which I think is a huge a challenge.”

Theme 4: Technology

In keeping with the focus on technologies in the broadest sense as part of our TVN funding grant:

- *Medication, device, knowledge product, improvement strategy or tool*
- Used for the diagnosis, treatment or palliative care of the seriously ill, frail elderly

For our focus groups, we asked how technologies, such as computers and the internet, can serve to bridge information gaps and needs in end of life preparedness among older LGBTQ adults.

Theme 4 (cont.)

- Variable use of technology to connect with others, for seeking information, staying in touch with family
- Use of computer technology as both helpful and potentially negative
- Fear of breaches of privacy (esp., Facebook)
- Concerns with accuracy of information found online
- Need for concise, accurate information (such as online factsheets)
- Use of 1-800 lines for information on end-of-life information and resources

Theme 4: Quotes

"The internet is fantastic. It is my social circle, almost."

"So I would never get into a social media situation where you're communicating with the masses… anywhere where your information is shared and you've got no control over it, I don't like that. I'll stay away from that."

"I belong to a website… for people who are living with chronic conditions… but it would be a good site to… chat about some of those end-of-life decisions as well."

"So I've used technology to make a lot of new friends and to broaden my own perspective. And feel comfortable in my own skin… "

Theme 4: Quotes (cont.)

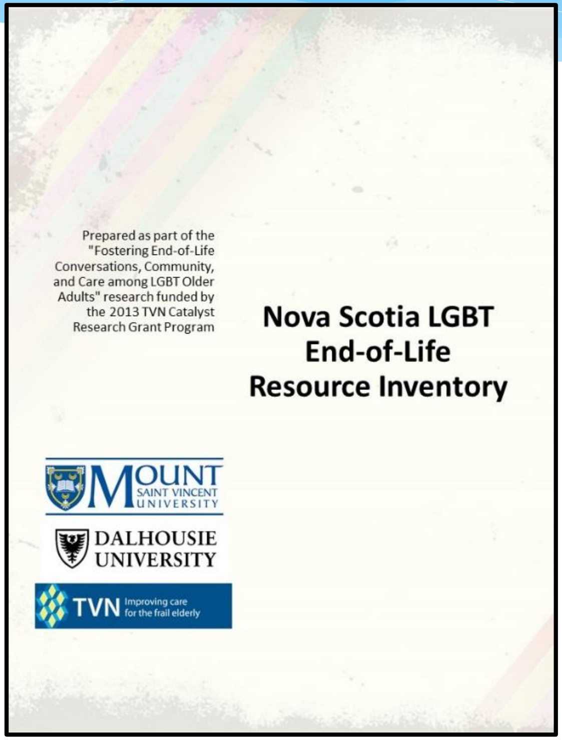
"I dislike technology, except I use some of it, the ones that I need…"

"…resources, that you could Google, that you could look up and having those in one place, that are really good pieces of information. Things like, like I said, how to write a living will…what you might want to think about in terms of your end-f-life."

"…a website or if you have a question and answer format someplace where you could look it up."

Nova Scotia Resource Inventory

- Social Resources
- LGBT Organizations
- End-of-life resources



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**Nova Scotia LGBT
End-of-Life
Resource Inventory**

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