

# LGBT Individuals and End-of-life Preparation: Nova Scotia Findings and Policy Implications

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# Introduction

- Older LGBT individuals often described as an invisible population due to past and present experiences of stigma and discrimination
- Higher rates of health issues compared to heterosexual individuals, rooted in past experiences (minority stress theory)
- Unique health concerns (e.g., transgender population)
- More likely to live alone, not have a partner or children, rely on formal supports
- Fear being in a LTC facility
- \*\* EOL care and plans particularly important

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- ▶ Little Canadian research on older LGBT individuals\*, including EOL issues
  - ▶ What are their thoughts about EOL planning and the role that technology might play in supporting EOL discussions?

Exceptions:

Brotman, S., Ryan, B., & Cormier, R. (2003). **The health and social service needs of gay and lesbian elders and their families in Canada.** *The Gerontologist*, 43, 192-202.

Brotman, S., Ryan, B., Collins, S., Chamberland, L., Cormier, R., Julien, D., Meyer, E., Peterkin, A., & Richard, B. (2007). **Coming out to care: Caregivers of gay and lesbian seniors in Canada.** *The Gerontologist*, 47, 490-503.

Murray, E., Numer, M., Merritt, B., Gahagan, J., & Comber, S. (2012). **Healthy aging among LGBT seniors in Canada: A review of the literature.** *International Journal of Health, Wellness & Society*, 1, 179-192.

# Halifax Sample

## Four focus groups

- Bisexual and gay men- 8
- Bisexual women and lesbians- 6
- Transgender individuals- 2
- Service providers- 4

## LGBT participants

- Age: 67 (average), range: 59 – 82
- 44% single, 13% domestic partnership or married, 38% in other partnerships
- Relationship duration: 1.5 – 66 years
- 31% had children

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- 44% lived alone
  - High levels of being out to others
  - Highly educated group
  - 31% not sure who their caregiver would be
  - Range of EOL preparation
  - Varying chronic health conditions (e.g., arthritis, depression, AIDS, diabetes)



## Service Providers

- 4 women
- 1 lesbian, 1 bisexual woman, 2 heterosexual women
- Range of professions
- 3 had specialized aging training, all had specialized training in working with LGBT clients
- Had worked in their fields between 6 – 33 years



# Four Themes

- Communities of care changed over time
  - Difficulty asking people for help
  - Hesitancy to think about EOL issues
  - Varying views about technology
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# Theme 1: Communities of Care Changed over Time





*“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





*“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?’”*

*“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 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 EOL Issues





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

“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.”

“I got quite ill back in ‘96 and so I was strongly encouraged to do all the preparations. . . . Now it’s all out of date.”

“Something else is how comfortable they are discussing their health, which many people aren’t. And possibly if there’s an HIV diagnosis. . . that with other people which I think is a huge a challenge.”

“In the trans community, they’re just trying to feel okay about where they’re at now. . . . Thinking about death and dying, they’re thinking about trying to live.”

# Theme 4: Varying Views About Technology





*“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.”*

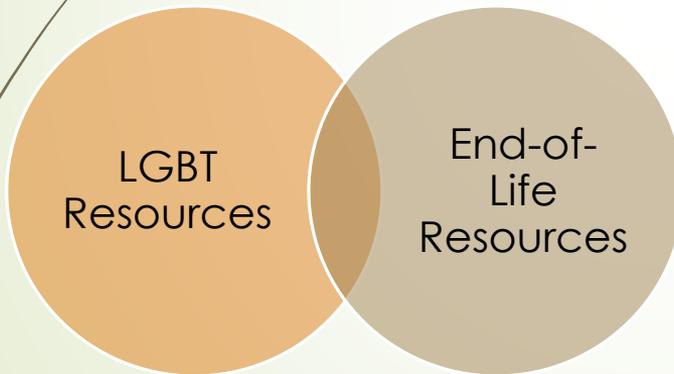
*“I belong to a website...for people who are living with chronic conditions...but [having one that was LGBT focused] would be a good site to... chat about some of those EOL decisions as well.”*

*“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.”*

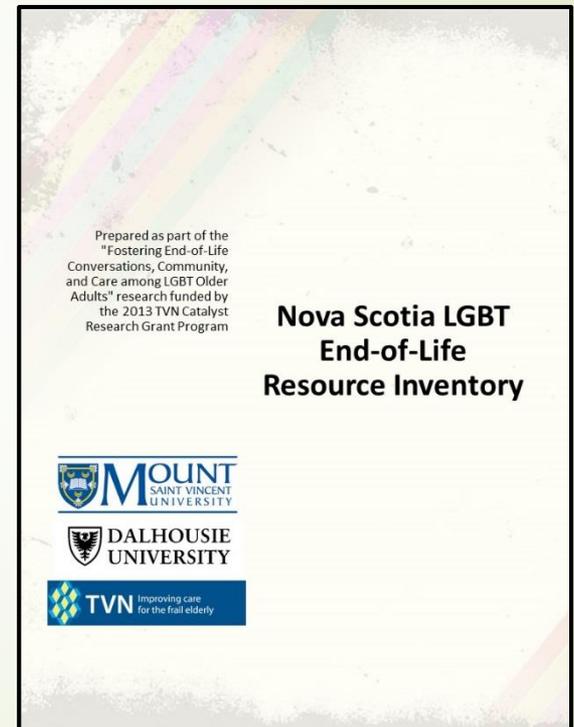
*“...resources that you could Google, that you could look up and having those in one place, that are really good pieces of information. Things like, like I said, how to write a living will...what you might want to think about in terms of your end-of-life.”*

# Nova Scotia Resource Inventory

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



<http://dal.ca/gahps/lgbteol>



# The Nova Scotian Context

- ▶ Rights and needs of LGBT individuals gradually being recognized in provincial policy and programs
  - ▶ Creation of PrideHealth (Capital Health District) (1996)
  - ▶ Provincial legalization of same-sex marriage (2004)
  - ▶ *Transgendered Persons Protection Act* (2012)
    - ▶ Amended the Human Rights Act (1991) by adding gender identity and gender expression
  - ▶ 8 types of sex reassignment surgery covered by NS Health (as of April 1, 2014)
  - ▶ Included as an underrepresented population in consultations for the Nova Scotia Dementia Strategy, and will be included in implementation of the strategy
  - ▶ Transgender Nova Scotians can identify their preferred gender on their birth certificates (Sept 2015)



Many health-related documents talk about culturally competent practice

- ▶ Primary Health Care using frameworks such as “Cultural Competency Guidelines”
  - ▶ <http://novascotia.ca/dhw/diversity/>
- ▶ NS Health & Wellness report “Integrated Palliative Care” notes that palliative care much be, among other things, culturally competent, safe and inclusive.
  - ▶ <http://novascotia.ca/dhw/palliativecare/>



Various organizations have online resources, such as

- ▶ Advance care planning documentations at Nova Scotia Hospice Palliative Care Associations
  - ▶ <http://nshpca.ca/resources/filter/advance-care-planning/>
- ▶ Personal Directives information at NS Health and Capital Health
  - ▶ <http://novascotia.ca/just/pda/>
  - ▶ <http://www.cdha.nshealth.ca/patients-clients-visitors/preparing-your-hospital-stay/personal-directives>

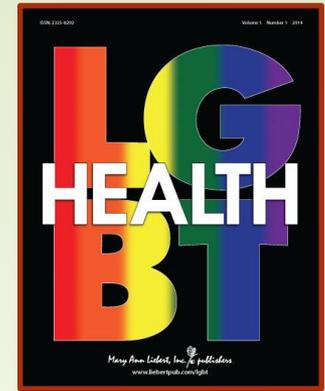
Other initiatives

- ▶ NSRAP (Nova Scotia Rainbow Action Project)- advocacy group (1995)
- ▶ Some long-term care facilities working on identifying LGBT needs, such as Northwood

# YET...

- ▶ How are frameworks about culturally competent practice implemented, with regard to LGBT older individuals?
- ▶ *NS Personal Directives Act (2008)* is based on heteronormative assumptions about caregiving.
  - ▶ If no personal directive created, a list of “nearest relatives” is used to assign a substitute decision-makers. Communities of care are not reflected in this.
- ▶ Recent NS research (Gahagan, 2015) indicates that 40% of individuals in the LGBT community did not access health-care services because their primary health care provider made assumptions about their sexual orientation or gender identity/expression.
- ▶ EOL research may be focusing on other underrepresented groups, such as African Nova Scotians, children, and those living in rural areas.
  - ▶ [http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report\\_ICES\\_urveillance2008.pdf](http://www.dal.ca/content/dam/dalhousie/pdf/sites/nels/report_ICES_urveillance2008.pdf)
- ▶ There is information available online, but do people know how to access it?

# Implications



- ▶ Although there is a growing interest in 'healthy aging', additional supports are needed to assist those from the LGBT communities to make EOL care decisions in Nova Scotia.
- ▶ This issue is particularly challenging for the generation of 'post-Stonewall' LGBT populations who may feel they need to 'go back into the closet' to access care.
- ▶ Curriculum and training scenarios for medicine and health professions students and CME are warranted (RIM/IPHE).
- ▶ The role that technology can play in EOL care and discussions needs further exploration.

suggested competencies

Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emler, C. A., & Hooyman, N. R. (2015). **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.

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