FOSTERING END-OF-LIFE CONVERSATIONS, COMMUNITY AND CARE AMONG LGBT OLDER ADULTS

GLORIA GUTMAN, SIMON FRASER UNIVERSITY
TVN MINDMERGE, VICTORIA, BC NOVEMBER 10, 2010 ESDAY, MAY 26, 2015
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Thank you to our funder, Technology Evaluation in the Elderly Network (TVN).
UNIQUE CHALLENGES FACING OLDER LGBT ADULTS

1. Effects of stigma, past and present
   - 1.6 million LGBT elders; largely closeted
   - A psychiatric disorder (until 1973)
   - Criminal (until 2003)
   - Limited legal protections
   - Fear accessing health and community services

2. Need to rely upon “families of choice” for care and support
   - Twice as likely to be single; age alone
   - Four times less likely to have children
   - Rely on friends (70%) who lack legal and social recognition
   - Uncertain “who caregiver will be”

3. Unequal treatment under laws, programs and services for older adults
   - Design safety nets around marriage, then exclude LG couples
   - Over 80% of LGBT adults report they “can not be out” in LTC settings

Effects of stigma, past and present

Unequal treatment under laws, programs and services for older adults

Need to rely upon “families of choice” for care and support
SOCIAL CONTEXT

Relative to heterosexual men and women of comparable age, LGBT older adults are:

More likely to live alone (especially gay men—2-3X: ref: Fredriksen-Goldsen et al., 2010; Wallace, Cochran, Durazo & Ford, 2011)

Less likely to have a partner/spouse (especially gay men—2-3X: ref: MetLife Mature Market Inst., 2010)

Less likely to have children (especially gay men—~4X: ref: Fredriksen-Goldsen et al., 2010)

More likely to rely on formal services and informal supports in non-traditional ways (i.e., friends)
BACKGROUND

“It’s too early—until it’s too late.”

Not talking about our future care need = a failed experiment

Consider the following:

- More than 90% think it is important to talk to loved ones about end-of-life wishes—less than 30% have had such discussions (Conversation Project, 2013; national sample)
- 60% of people report it is “extremely important” that their loved ones are not burdened by tough decisions; almost 60% have not communicated their wishes (CA Healthcare Foundation, 2012, n=1669 adults)
- 70% of people say they would prefer to die at home; 32% of deaths take place at home (CA Healthcare Foundation, 2012, n=1669 adults; CA DPH, Death Records, 2011)
LGBT PERSONS IN LONG-TERM CARE SETTINGS

Can LGBT older persons be “out” in LTC setting?

LGBT OLDER PERSONS (65+) (N= 278)
- Yes: 78
- No: 22

CAREGIVERS, OTHERS (N=466)
- Yes: 84
- No: 16

Fears/expectations of LGBT older persons in LTC settings:

- DISCRIMINATION BY RESIDENTS: 81%
- ISOLATION FROM OTHER RESIDENTS: 77%
- DISCRIMINATION BY STAFF: 89%
- ABUSE, NEGLECT BY STAFF: 53%
PROJECT DETAILS

Three-part national project

- Focus groups with LGBT older adults and care providers in Vancouver, Edmonton, Toronto, Montreal, and Halifax to understand issues/extent of end-of-life planning (e.g. document completion, care planning, discussions)
- Town hall meetings to raise awareness of need for planning and to highlight local resources
- Create proof-of-concept pilot web-based platform to provide supportive environment for information sharing and community building:
  http://sfu.ca/lgbteol
**STUDY SAMPLE**

<table>
<thead>
<tr>
<th></th>
<th>Bisexual &amp; Gay Men</th>
<th>Bisexual &amp; Lesbian Women</th>
<th>Transgender Individuals</th>
<th>Sub-Total</th>
<th>Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>39</td>
<td>29</td>
<td>23</td>
<td>91</td>
<td>26</td>
</tr>
<tr>
<td>Vancouver</td>
<td>15</td>
<td>12</td>
<td>9</td>
<td>36</td>
<td>7</td>
</tr>
<tr>
<td>Edmonton</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Toronto</td>
<td>5</td>
<td>4</td>
<td>9</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Montreal</td>
<td>6</td>
<td>5</td>
<td>2</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Halifax</td>
<td>8</td>
<td>6</td>
<td>2</td>
<td>16</td>
<td>4</td>
</tr>
</tbody>
</table>

Age range 57-89 years; M = 69
FOSTERING END-OF-LIFE CONVERSATIONS – FOCUS GROUPS

Four Focus groups at each site:
• Gay and bisexual men
• Lesbians and bisexual women
• Trans* identified persons
• Service providers

Requirements for LGBT groups:
• English or French speaking
• 60 years of age or older
• One or more chronic conditions
• Some Internet experience

Content:
• Preparations, plans for later life care
• Issues, concerns about aging
• Role of community and support
• Role of technology in assisting LGBT persons better prepare

• Group discussions recorded, transcribed, coded (by two persons)
# Focus Group Participants Characteristics

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>% Single</th>
<th>% Live Alone</th>
<th>% No Children</th>
<th>% No Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gay Men</td>
<td>39</td>
<td>62</td>
<td>72</td>
<td>77</td>
<td>32</td>
</tr>
<tr>
<td>Lesbians</td>
<td>29</td>
<td>48</td>
<td>45</td>
<td>48</td>
<td>30</td>
</tr>
<tr>
<td>Trans*</td>
<td>23</td>
<td>70</td>
<td>54</td>
<td>33</td>
<td>38</td>
</tr>
</tbody>
</table>
## FOCUS GROUP THEMES - EDUCATION

<table>
<thead>
<tr>
<th>Bisexual &amp; Gay Men</th>
<th>Bisexual &amp; Lesbian Women</th>
<th>Transgender Individuals</th>
<th>Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Education of service providers about LGBT issues</td>
<td>• LGBT individuals need to self-educate about aging &amp; about palliative care</td>
<td>• Intentional, specific education</td>
<td>• Diverse backgrounds of care providers</td>
</tr>
<tr>
<td>• Politicize issues</td>
<td>• Plans change when partner gets sick</td>
<td>• Need “bottom-up” education</td>
<td>• Learning diversity of language (e.g. LGBTQ, 2-spirit, intersex)</td>
</tr>
<tr>
<td>• Educate younger persons</td>
<td></td>
<td>• Need to educate medical residents, care facility staff, and other older adult LTC residents</td>
<td></td>
</tr>
</tbody>
</table>
## EXCLUSION IN HEALTHCARE SETTINGS

<table>
<thead>
<tr>
<th>Bisexual &amp; Gay Men</th>
<th>Bisexual &amp; Lesbian Women</th>
<th>Transgender Individuals</th>
<th>Service Providers</th>
</tr>
</thead>
</table>
| • Concern about having to “go back into the closet” to receive care | • Residential services not LGBT-affirmative, and “more focused on wealthy gay men”  
• Concern about having to “go back into the closet” to receive care | • Anxieties of having to “out self” in each new medical environment; having to educate health providers  
• Forms that don’t describe “who I am” | • No one knows what happens “behind closed doors” |
## LANGUAGE

<table>
<thead>
<tr>
<th>Bisexual &amp; Gay Men</th>
<th>Bisexual &amp; Lesbian Women</th>
<th>Transgender Individuals</th>
<th>Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• End-of-life planning resources focus on heterosexual scenarios</td>
<td>• Need to recognize within group diversity (“I’m a gay female; the one word I don’t use is lesbian”)</td>
<td>• No consideration for long-term needs for transgender individuals in healthcare materials</td>
<td>• Difficulty balancing changing language (e.g. “queer”) with client needs and preferences</td>
</tr>
</tbody>
</table>
## STIGMA, DISCRIMINATION, STEREOTYPING

<table>
<thead>
<tr>
<th>Bisexual &amp; Gay Men</th>
<th>Bisexual &amp; Lesbian Women</th>
<th>Transgender Individuals</th>
<th>Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Impact of living with HIV/AIDS</td>
<td>• Impact of living with HIV/AIDS (e.g. “I lived my life dying of AIDS. Literally, that’s the way the world looked at me – dying. .... the medical profession still views me as a body with AIDS rather than an aging female.”)</td>
<td>• Discrimination from within as well as outside the LGBT community</td>
<td>• Diverse background &amp; training of care providers</td>
</tr>
<tr>
<td>End-of-Life Planning</td>
<td>Gay men</td>
<td>Lesbians</td>
<td>Trans</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------</td>
<td>----------</td>
<td>--------</td>
</tr>
<tr>
<td>Will</td>
<td>73</td>
<td>67</td>
<td>89</td>
</tr>
<tr>
<td>Living will</td>
<td>33</td>
<td>58</td>
<td>22</td>
</tr>
<tr>
<td>Durable POA</td>
<td>40</td>
<td>50</td>
<td>33</td>
</tr>
<tr>
<td>Representation Agreement</td>
<td>7</td>
<td>42</td>
<td>11</td>
</tr>
<tr>
<td>Pre-paid Funeral</td>
<td>27</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>LTC Insurance</td>
<td>13</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Critical Care Insurance</td>
<td>13</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Informal care arrangement</td>
<td>40</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Explicit care discussion</td>
<td>47</td>
<td>75</td>
<td>78</td>
</tr>
<tr>
<td>Explicit EOL discussion</td>
<td>40</td>
<td>67</td>
<td>78</td>
</tr>
</tbody>
</table>
LONELINESS & ISOLATION:
THE BEST LAID PLANS

“But what did shock me... I had 6 close teaching friends, all my age, we all retired exactly the same day, and within 2 years all of them were dead.... And so whatever retirement I thought I was going to have involving those people, and we were all single just went, and so I had to invent, I had to figure out a new way of doing it because I just had counted on those people being around.” (Edmonton)

...and my partner passed away a year and a half ago so, this is, we thought we had everything covered, when it was the two of us, but now everything has changed. (Vancouver)
SUMMARY

• Many similarities; important differences between gays, lesbians and trans persons
• Lack of, and need for, conversations about end-of-life care with non-traditional caregivers
• Attend to the differences within the LGBTQ population
  • Legacy of HIV
  • Differential access to resources (economic, social)
  • The “hidden T”
• Attend to heteronormativity of health care settings
• Service providers “got it;” not sure how to “act on it” and know they can do better
CONCLUSIONS

Older LGBT adults face significant and unique challenges in planning later-life and end-of-life. Recognizing and addressing these challenges may redress the exclusion of LGBT persons as well as others who age alone, support better preparation and person-centered approaches to care.

Older LGBT adults have additional/unique end-of-life planning challenges.

Inclusive education and policies may redress...
IMPACT ON POLICY

Policies for aging and older adults need to consider issues of sexual orientation and gender identity.

Service provider education needs to include cultural competence (including knowledge and understanding of socio-political history and context).

Resources need to be inclusive and accessible to older LGBT adults.