

## Developing a web-based platform to foster end-of-life planning among LGBT older adults

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**Background** LGBT aging shares much in common with aging in general; however, a significant dimension of difference lies in the pervasive marginalization and discrimination that LGBT older persons have experienced in a heteronormative environment. **Aims** Our project focused on the development of a web-based platform to provide a supportive environment for sharing end-of-life information and building a community among older LGBT individuals. **Method** This study employed a qualitative methodology. Focus groups were held with research participants to explore end-of-life planning issues as well as the roles of technology and the Internet in their lives. Using an iterative design model, these focus groups informed the development of the LGBT End-of-Life Conversations website and resources such as the British Columbia LGBT Resource Inventory. **Results** Based upon website traffic statistics and user feedback obtained as part of our iterative design loop, the website has been successful; however, the Discussion Forum component of our website was not well utilized. **Conclusions** An iterative design proved effectiveness of website design, targeting effective in the design of our website targeted toward older LGBT persons, members of a marginalized community.

**Keywords:** LGBT, end-of-life, iterative design, web-based community

This paper describes the third phase of a three-phase national project, designed to foster end-of-life planning and to build a community among Canadian Lesbian, Gay, Bisexual and Transgender (LGBT) older adults. In Phase 1, focus groups were held with LGBT older adults and service providers to older adults in Vancouver, Edmonton, Toronto, Montreal and Halifax to understand the issues and the extent of end-of-life planning that members of this population have undertaken (e.g. had they prepared a will or advance care directive, given power of attorney or determined who might provide care should they need it). In Phase 2, Town hall meetings were held to report back our findings, raise awareness of the need for end-of-life planning and to familiarize the LGBT older adult community with local resources and services. In phase 3, a web-based platform was designed based on the previous steps to create a supportive environment for information sharing and community building. This last phase, informed by the Vancouver focus groups is the focal point of the work reported herein. In this phase, based on participant feedback, we expanded our conceptualization of end-of-life planning, beyond document preparation and discussion, to include health care, housing, psychological and social support and the spiritual dimension needs in later life.

### WHY CONSIDER LGBT OLDER ADULTS

While LGBT aging shares much in common with aging in general; a significant dimension of difference lies in the pervasive marginalization and discrimination that LGBT older persons have experienced in the heteronormative environment of their formative years and over the course of their lives<sup>1</sup>. Orel & Fruhauf have compiled a comprehensive list of historical events that have shaped the lives of LGBT adults in the United States<sup>2</sup>. Some of these events include: the McCarthy era labeling gays as subversive in the 1950's; having one's sexuality defined as a mental illness by the American Psychological Association until 1973; watching Anita Bryant run the anti-gay 'Save our Children' campaign in 1977; and the AIDS crisis which in 1981 was referred to as a gay-related infectious disease (GRID) and considered by many to be self-inflicted. The Canadian Broadcasting Corporation compiled a similar 'calendar of events' for its Gay & Grey series<sup>3</sup>, particularly highlighting the fact that homosexuality was illegal in the early part of these people's lives and was not decriminalized in Canada until 1969<sup>4</sup>.

Meyer has described these experiences, and the responses they engender within individuals, as representative of minority stress<sup>5</sup>. Minority stress

is a model that has been applied to a number of populations such as immigrants, women, racial, and ethnic minorities<sup>6</sup>. Meyer's adaptation of the model to LGBT populations, is based upon the premise that LGBT people, like those in other minorities, are subject to chronic stressors that are related to stigma<sup>7</sup>. Such stressors are defined as enacted stigma (referring to explicit behaviors, for example a homophobic slur), felt stigma (referring to adaptive behaviors taken to avoid anticipated acts of discrimination, such as concealing one's identity), and internalized stigma (which has been described as accepting society's view of one's group as legitimate)<sup>5,8,9</sup>. LGBT older persons have experienced these stressors over many decades and continue to endure stigma – often daily (e.g., in decisions of whether or not to identify as LGBT in everyday interactions).

Meyer's model further differentiates among general, distal, and proximal stressors<sup>5</sup>. While General stressors may affect all people at some time or another in their lives, Distal minority stress processes refer to those that manifest in the environment directly related to sexual orientation such as discrimination and violence. The distal minority stress processes and one's recognition of being a member of and identified as a sexual minority provide a pathway to the proximal minority stressors. These stressors include expectations of rejection, concealment of one's identity, and internalized homophobia, which lead to many and significant emotional, physical, and social health consequences<sup>7,10-12</sup>. Wallace et al. have reported that sexual orientation is itself a determinant of health disparities – recently proclaimed by the U.S. National Institutes of Health<sup>13</sup>. These disparities in comparison to similarly aged heterosexual adults include increased loneliness, poorer mental health, more lifetime suicide attempts, increased likelihood to smoke or drink alcohol in excess, and a higher degree of chronic conditions such as human immunodeficiency virus, cardiovascular disease and some cancers<sup>11,12,14</sup>. Furthermore, relative to heterosexual men and women of comparable ages, LGBT older adults are more likely to live alone (three times more likely for gay men with 60% living alone) and one and a half times more likely for lesbians (with 30% living alone)<sup>8</sup>. Many in this cohort believed that marriage between same-sex couples was not possible during their lifetime; perhaps relatedly, gay men are up to three times less likely to be partnered (25% have partners) and lesbians about half as likely (37% are partnered) as their heterosexual counterparts<sup>13,15,16</sup>. The possibility for both gay men and lesbians to have children is 5 times lower; moreover, among 15% who had children, over 60% reported that their children were not available to assist them<sup>12</sup>. It is thus not surprising that LGBT older adults often rely upon friends in times

of need and support, sometimes characterized as 'fictive kin' or 'families of choice'<sup>17,18</sup>. Recent writings point out the challenges experienced by these non-family caregivers in a family-centric health care environment<sup>19,20</sup>.

These limited (and non-familial) support networks however, may also exacerbate tendencies toward procrastination or avoidance of end-of-life conversations and planning in this community<sup>16</sup>. Caregiving research reveals a heteronormative pattern of support seeking where care is both expected and first sought from spouses, then adult children or other family members, then more distant kin and friends, followed by formal organizations and services<sup>21</sup>. Substantial research notes that LGBT older adults are suspicious of health care institutions and consequently delay seeking formal care<sup>16,22</sup>. In the general population of older adults, conversations about end-of-life planning, when they occur, are largely family-centered. By virtue of the demographics reported above, LGBT persons infrequently turn to kin for support and are even less likely to have conversations about care. It is imperative to find a way to nurture and support such conversations.

## WHY A WEB-BASED PLATFORM

The growth in use of computers and concomitant increase in Internet use have been dramatic in the older adult population. In Canada, the most comprehensive data on Internet use, collected in 2007, reported that 90% of Canadians aged 65 and over, regularly used email and 54% surfed the Internet for fun and leisure<sup>23</sup>. More recent data from the United States reports that 59% of American seniors used the Internet regularly in 2013, compared to just 22% in 2004<sup>24,25</sup>. The baby boom generation – i.e. those born between the years of 1946 and 1964 (now aged 52-70) – is reported to use computers and the Internet in proportions comparable to younger cohorts<sup>26</sup>. The Internet is used for a variety of tasks including but not limited to: communicating with friends and family; social activities (dating); and seeking health information<sup>27-30</sup>. Internet usage has been associated with a number of reported beneficial effects including decreased loneliness<sup>31</sup> and increased sense of community<sup>32</sup>. Gatto and Tak have further indicated that older adults have experienced a sense of connectedness and satisfaction when going online for communication<sup>33</sup>.

LGBT adults are described as being heavy users of social media sites in comparison to the general population<sup>34</sup>. The use of the Internet and social media reported by participants in our project suggests this trend includes the LGBT older adult population<sup>35</sup>. Smith et al. stated that LGBT-oriented legal advice, information about assisted living, and grief and loss counseling were among

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the greatest unmet health needs for LGBT older adults<sup>36</sup>. They further explained that the Internet was a viable means to reach this population. This research provided an evidence-base and a rationale for developing a website that would provide relevant information about necessary facilities and services, engage the older adult LGBT community in end-of-life planning dialogue and build a sense of community and connectedness among this population.

## OVERVIEW OF THE PROJECT

The development and implementation of the LGBT End-of-Life Conversations website was designed to be iterative in nature. By iterative we mean that we consulted with potential website users prior to the design and also during the development process and integrated their suggestions throughout: Figure 1 describes our process.

As can be seen, conceptualization was followed by focus group research conducted from August to October 2014 in Vancouver, British Columbia. In the focus groups we explored end-of-life planning issues, the analyses of which were presented elsewhere<sup>37</sup>, as well as the roles of technology and the Internet in their lives and how they might aid in end-of-life planning. The transcripts of the focus groups were formally analyzed for themes and these informed the development of our website. The focus group discussions also led to the proliferation of a set of LGBT-affirmative Resource Inventories, not envisioned when the project was originally conceived. These inventories, described below, array the local (municipal and provincial, in some cases) end-of-life services available to LGBT (and all) older adults and the extent to which these services are directed to or inclusive of LGBT issues and concerns. Fol-

lowing the completion of first drafts of these inventories, preliminary coding of the focus group transcripts, and the initial design of the website, a town hall meeting (attended by over 90 persons) was held in Vancouver wherein the work thus far was described and discussed, along with a review of the research and practice in this area, with presentations from key service providers as well as a lawyer whose work often includes LGBT persons. This meeting proved fruitful - both for the participants who responded with gratitude for what they had learned and the opportunity to talk about these issues and for the researchers who used this information to adapt the inventories (having learned of new resources) and the website. Revisions to the website were an ongoing effort (as described above) based on new information, insights and feedback.

## FOCUS GROUP FINDINGS

A total of four focus groups were held in Vancouver, comprising gay and bisexual men (n=15); lesbian and bisexual women (n=12); transgender persons (n=9); and service providers (n=7). All LGBT participants (M= 67.6 years, age range: 57 to 83 years), were English-speaking and living with at least one chronic condition. The focus groups were recorded, transcribed, and analyzed for themes. It is noteworthy that even as Internet access and usage were frequent and familiar to the majority of these participants, engagement with computers (and satisfaction with such engagement) varied from "little computer use" to "I nearly threw my computer out the window yesterday, it is so frustrating" to "I spend so much time alone, the computer can be a real check-in." Interestingly, little conversation was focused on website user requirements and issues (our participants were comfortable navigating most websites they encounter); among the suggestions offered

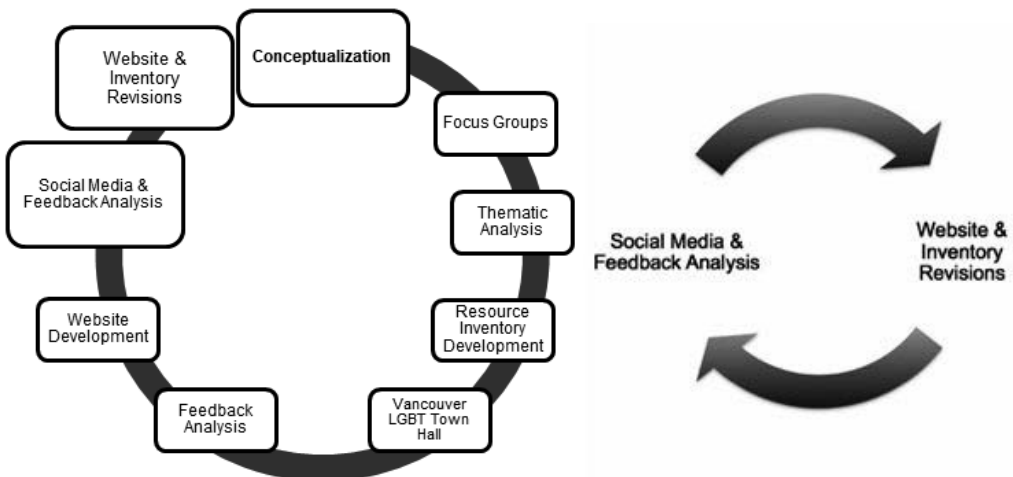


Figure 1. Conceptual model of our iterative research and development process

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were “limiting the number of links so as not to be overwhelming,” and being cognizant that “older people don’t always have a computer mindset.” The general focus group discussion overwhelmingly pointed to the need to develop and further promote end-of-life planning among LGBT older adults. For example, one of the gay male participants noted that:

*“Even easy issues haven’t been discussed, let alone hard issues; e.g. specifics of care provision; asking people to do difficult things; deal with own mortality”.*

Implication in the above quote is the absence of someone with whom to have such discussions – a sentiment shared by all participants and expressed in the following quote by a participant in the lesbian group:

*“Don’t know who will make decisions for me; have no one, so nothing to plan”.*

And one of our transgender participants expanded on the challenges of having no one:

*“when sick, can’t really speak for self–need an advocate”.*

We specifically called for comments about the roles of technology and the Internet in these older adults’ lives; many such comments revolved around the need for LGBT-relevant information: *“we needed to go to the heterosexual [websites]; when I went to queer ones...there wasn’t much”.*

In the search for LGBT-relevant and affirmative information, many focus group participants spoke of the need to determine LGBT-friendliness in the sites they were visiting, finding that: *“most websites are tailored to heterosexuals” and finding one that included LGBT reference provided “one less barrier”.*

Participants felt that an LGBT website should be accessible, credible and not overwhelming: “not more than 20 links,” as one gay man recommended.

The service providers agreed and felt the Internet, and particularly the proposed website could:

*“empower (LGBT) individuals (and) can give them a voice” which they believed was “especially important in rural, smaller communities”.*

Some research suggests that the Internet is providing rural dwelling LGBT persons, gay men in particular, with a sense of community, albeit virtual, where none existed before<sup>38,39</sup>. This was raised in our discussions as well as noting that even living just outside of the main metropolitan areas (e.g., outside of the “gay center”) challenges community – and hence planning and discussions about end-of-life. Providing a venue and forum for the nurturance of community (e.g.,

the website) was endorsed by many in our groups – with some qualifications. Our transgender participants for example, when envisioning a more interactive online community, warned that any discourse would need to be moderated and made: *“emotionally safe for the individuals to post, sensitive to take-over by a dominant voice, sensitive to age.”*

Such comments allude to the history of exclusion and mistreatment experienced by these older transgender (and LGBT) adults – the history of minority stress in their lives.

## WEBSITE DESIGN CONSIDERATIONS

The focus groups made it clear that being able to easily determine if a website is LGBT friendly is one less barrier. First and foremost, we endeavored to make our website LGBT friendly, with the use of photos depicting same-sex couples, rainbow flags, and a logo incorporating these rainbow themed colors (Figure 2).

In terms of content, the website describes our research team, our activities including presentations at public events and conferences, and it houses numerous resources including the British Columbia LGBT End-of-Life Resource Inventory described in detail below, and similar Resource Inventories subsequently developed for Edmonton, Toronto, Montreal and Halifax – the other sites in our study. In response to focus group commentary regarding safe spaces, we developed two interactive spaces on our website (Discussion Forum and LGBT news feed) where website users could post comments that would be moderated before going live. In our efforts to share information, we chose to include more than just written materials and links to other websites and developed nine videos which could be found under the menu tab ‘Conversations with Robert’. These videos cover topics such as ‘The impact of HIV/AIDS on LGBT aging’ and ‘LGBT aging and going back into the closet’. The website also contains a video of the Town Hall held in January 2015 at which the British Columbia Resource Inventory was launched and the URL for the website was first publicized. An elder abuse page was added in March 2016, hosting videos and posters developed in a unique and creative intergenerational project that brought together a group of queer older adult creative writers (Quirk-e), a queer youth activist group (Youth for A Change) and elder abuse/family violence researchers<sup>40</sup>. This page was added, in part, to illustrate community action/interaction and promote dialogue and communication.

## RESOURCE INVENTORY DEVELOPMENT

The Vancouver focus groups identified a need within the LGBT older adult community, and in particular among those in their later years, for information on existing resources for end-of-life



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planning and care. The focus groups also informed us that a way of knowing if the resources were LGBT-friendly was needed.

This led to the development of a typology to rank the friendliness of relevant health and social service organizations. This typology grew out of several iterations of discussions among researchers focusing on LGBT older adults as well as discussions with community groups and older LGBT adults. It was further member-checked, both formally and informally, by persons in the LGBT community as well as service providers. This iterative process ensured input and validity at many stages and was part of the broader reciprocal knowledge-transfer approach taken throughout this project. For example, in the development of the British Columbia LGBT End-of-Life Resource Inventory, it was discovered that end-of-life planning resource organizations and their websites had little mention of LGBT inclusivity and friendliness. We found that many formal organizations have employed the blanket term 'inclusive to all' and this often was interpreted by our LGBT respondents to mean that "we treat everyone the same", i.e., as heterosexuals. To navigate this vague descriptor, we developed a ranking system to evaluate LGBT-friendliness and applied it to end-of-life planning resources and services identified through an Internet search.

Internet searches were conducted between October and December 2014 by combining terms to describe the population (LGBT, lesbian, gay, bisexual, transgender, older adult, senior) with terms to describe the areas of interest (end-of-life planning, advance care planning, independent living, senior housing, retirement community, home care, assisted-living, residential care, health care, palliative care, and hospice). These searches were supplemented by referrals by our community partners and focus group participants. The

result was a 54-item end-of-life planning and care resource for LGBT British Columbian residents.

LGBT 'friendliness' was operationalized for each item using three tiers:

- (i) An 'LGBT Organization' - an organization that was developed by and/or for LGBT persons.
- (ii) An 'LGBT Friendly (formal)' organization - an organization that openly advertises LGBT friendliness on its website by the way of content such as mission statements, codes of conduct, or other LGBT inclusive statements. To be included in this category, such statements had to be LGBT specific; general statements such as 'we recognize diversity' did not qualify.
- (iii) An 'LGBT Friendly (informal)' organization - one that advertises as LGBT friendly in an LGBT directory or is referred to as LGBT friendly by an LGBT directory or is a service provider with links to the LGBT community. Such organizations however did not openly advertise LGBT friendliness on their websites nor include LGBT-affirmative statements in their mission statement or public documents.

## WEBSITE TRAFFIC

Collectively in the first 16 months after the launch of the website in March 2015, our website has seen gross traffic of 7049 users and 1684 "authentic" sessions (operationalized as a user visiting the site for 11-1801+ seconds, long enough to download a document or click a link to one of our resources). In this same time period, the 9 videos described above have been viewed over 2100 times. The addition of the elder abuse page increased the traffic substantially. The discussion forum however, has not been well used; it saw only a few users in the first thirty days after the website was launched. It is worthy of note that session duration, an indicator of user engagement, increases in months where members of our team participate in LGBT events. For



Figure 2. The LGBT End-of-Life Conversations website homepage

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example, in September 2015 we participated in BOLDfest (A lesbian conference held in Vancouver, BC) and in February and March 2016 our LGBT elder abuse town halls were held.

## WEBSITE AND INVENTORY FEEDBACK

The ultimate goal of our project was to develop a website and LGBT resource inventory that would continue in perpetuity. We did not formally develop an evaluative instrument to gauge user receptivity of our website and inventory. Rather, we envisioned an end-product with an ongoing feedback loop continually connecting website and inventory revisions with social media and feedback analysis (Figure 1). Social media brought to us comments about our website by end-users of platforms such as, but not limited to, Facebook and LinkedIn. More traditional forms of feedback, such as in-person commentary collected during our town hall meeting, and emails that we encouraged community members to send to our webmaster have also contributed to our website revisions.

## Website

After the launch of our website in March 2015, we received feedback that was generally positive, attesting to an unmet need our website was filling in the LGBT community. A gay man in his 60's living with HIV posted a message on Facebook commenting:

*"Luv the website...I have been on the site for a couple of hours."*

An older woman posted that our website was:

*"A badly needed resource. Thank you for sharing this information."*

A practitioner emailed:

*"Very happy to see this is now up and active after all the effort and care that went into this project. I believe it will truly go a long way indeed to relieving much anxiety, confusion and isolation associated with end-of-life decisions."*

Numerous organizations concerned with death and dying asked to link to our website. A bi-lesbian director inquired by email:

*"We are delighted to add this new BC resource to our directory."*

Another asked:

*"There are several videos on your page 'Conversations with Robert', which I found moving and helpful. We are wondering if you would consider allowing us to post them in our own video gallery on our website?"*

The feedback was not free of critique, several users commented on the term 'end-of-life' and a 68-year-old gay man who contacted us through email noted:

*"When I introduced a friend to the new website: LGBT End of Life Conversations, she immediately concluded that it was about HOSPICE resources."*

The positive commentary was certainly welcome and motivated our team to search for new resources to add to the website. The confusion about the term 'end-of-life' was useful and we reviewed our home page to ensure that we had noted the breadth of end-of-life concerns included health, housing, psychological and social support and the spiritual dimension. The addition of our 'LGBT Elder Abuse' page in March 2016 also provided us with an opportunity to further define and expand our scope in regard to whom we are targeting our end-of-life resources.

## LGBT resource inventory

The LGBT resource inventory received a first round of external feedback at our Vancouver town hall meeting and additional feedback after the launch of our website. We received a great many positive comments about this "remarkable" resource with word that one 60+-year-old gay man, shared a link to our resource inventory with 120 members of a closed Facebook group.

It is worthy of note that services and organizations included in the inventory also reported finding the exercise of reflecting on their LGBT-inclusiveness useful and instructive. One executive director – a gay man – of a senior social service agency believed his agency, located in an area of the city heavily populated by LGBT (older) persons, was very LGBT friendly. In our review of the website and other publicity of this agency, we listed the agency as LGBT-friendly (Informal), given its informal association with the LGBT community (primarily based on its location and association with other LGBT service providers). The executive director was startled to learn this and realized that he needed to change the agency's presentation to the community to ensure prospective and current members' realization of their commitment to the LGBT community. Symbols representing LGBT-affirmation soon appeared on their website and in other documents to signal their welcome and the safety of this agency for LGBT older persons. The inventory was adjusted accordingly.

In addition to having the organization described above requesting an upgrade in LGBT-friendliness, we also received numerous suggestions from the LGBT community, both individuals and organizations, in regard to potential resource additions. As a result, our BC resource inventory has grown to 65 listings. We believe this is the result of our iterative design as well as our promotion of the website as an interactive 'community' for LGBT older adults.

## DISCUSSION: INSIGHTS AND LESSONS LEARNED

We developed the LGBT End-Of-Life Conversations website taking into consideration the design suggestions received during our focus group research, with further refinements based on input from both LGBT older adults and service providers. Our goal was to share information, and provide a venue for such sharing – between researchers and participants and among participants themselves. The focus group research confirmed that a lack of information about the LGBT-friendliness of resources, and the context within which such resources are often presented, has the potential to impact and delay health care and end-of-life planning – as suggested by minority stress theory. A set of LGBT End-of-Life Resource Inventories were developed to address this need. The positive reception to both our resource inventory and website attests to the need for the development of LGBT specific and friendly resources. This is especially true for the older cohort of LGBT seniors who came of age in an environment hostile to homosexuality.

Our project also supports the use of an iterative design model where potential website users were consulted and engaged in the process from inception to our final iterative loop that will continue in perpetuity. It is interesting to

note that the relative success of our website is concomitant with an environment in which more and more older adults are using the Internet<sup>23-25</sup>. Further, a website such as ours can provide resources for caregivers of LGBT older adults - both formal and informal.

From a lessons learned perspective we found it insightful to note that in spite of focus group commentary suggesting a desire for a safe space to share end-of-life stories and challenges, our website Discussion Forum has seen little traffic. The message board style forum that we created has seen a ten-year trend in declining usage among all types of users<sup>41</sup> and has difficulty in competing with preferred social media forums such as Facebook, where closed groups are now providing the LGBT community with the safe spaces to communicate as they desire. Simply stated, it appears that those seeking end-of-life planning information are much like Internet users seeking health information where the trend has been for individuals to consume information versus contributing to the dialogue<sup>42</sup>. An iterative design proved the effectiveness of website design, targeting toward older LGBT persons; the site generated both interest and appreciation, partially filling a virtual void for a marginalized community.

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