

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

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 experiences in the heteronormative environment of their formative years and over the course of their lives

1. Orel & Fruhauf have compiled a comprehensive list of historical events that have shaped the lives of LGBT adults in the United States. 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, particularly highlighting the fact that homosexuality was illegal in the early part of these people's lives and was not decriminalized in Canada until 1969⁴.

Meyer has described these experiences, and the responses they engender within individuals, as

is a model that has been applied to a number of populations such as immigrants, women, racial, and ethnic minorities⁶. 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 stigma⁷. Such stressors are defined as enacted stigma (referring to explicit behav

the greatest unmet health needs for LGBT older adults³⁶. 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 elsewhere³⁷, 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

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

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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

