

The Role of Information and Communication Technology in End-of-Life Planning Among a Sample of

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aged 55 to 89. Constant comparative analysis yielded four categories: (a) fear, (b) individual benefits, (c) social elements, and (d) contextual elements. Fear related to technology and fear of end-of-life planning. Individual benefits referred to technology as a platform for developing LGBT identities and as a source of information for later-life planning. Social elements were establishment and maintenance of personal relationships and social support networks. Contextual elements referred to physical and situational barriers to technology use that limited access and usability. These findings can inform technological practice and services to enhance later-life planning.

Keywords

bisexual, lesbian, gay, transgender, later-life planning, Internet and communication technology

Information and communication technologies (ICT) can help maintain and enhance quality of life for older adults (Erickson & Johnson, 2011; Gatto & Tak, 2008). Although much research on older adults' use of technology focuses on potential barriers (e.g., Charness & Boot, 2009), population-based data show that a substantial percentage (more than 40%) of adults above age 65 use ICT (Gell, Rosenberg, Demeris, LaCroix, & Patel, 2013). Older adults use ICT to access information on health and wellness, and communicate with family and friends (Vroman, Arthanat, & Lysack, 2015; Yoon, Jang, Vaughan, & Garcia, 2018). ICT use can play a role in informed decision-making about health issues, later-life planning, and end-of-life planning (Cajita, Whitehouse, Budhathoki, & Hodgson, 2016; Carr & Khodyakov, 2007). Consideration of the individual and social contexts that influence ICT use is important for maximizing older adults' engagement with technology (Rogers & Fisk, 2010; Wahl, Iwarsson, & Oswald, 2012). Older adults with diverse sexual orientations and gender identities (e.g., lesbian, gay, bisexual, and trans [LGBT]) represent individual and social contexts that are often overlooked (Brown, 2009).

LGBT adults have developmental needs similar to cisgender heterosexual adults who also may use technology to help overcome isolation and stigmatization. However, lesbian, gay, and bisexual adults, and trans adults in particular experience greater stigmatization and social isolation compared with the general cisgender heterosexual population of older adults (de Vries, 2013; Finkenauer, Sherratt, Marlow, & Brodey, 2012; Fredriksen-Goldsen, et al., 2014). These factors likely create unique benefits of and barriers to ICT use (Brotman, Ryan, & Cormier, 2003; Meyer, 2003). The Internet has been a valuable networking tool for those with stigmatized identities, helping people

find similar others to share experiences and coping resources (Bargh & McKenna, 2004). However, online communities and sources of information can be hostile for LGBT adults (Fredriksen-Goldsen et al., 2014; Hughto, Reisner, & Pachankis, 2015), adding to concerns beyond the typical ones older adults may have about ICT use (Charness & Boot, 2009). Thus, the purpose of this study was to examine technology use among LGBT older adults with a focus on later-life planning, social integration, and potentially unique factors linked to diverse sexual orientations and gender identities. Later-life planning includes planning for all activities associated with life transition and advancing age (e.g., retirement planning, living arrangements, health care, power of attorney, end of life arrangements, etc.).

Rates of ICT Use Among Older Adults

Little research has examined the rates and nature of ICT use among LGBT older adults; however, research not examining diverse sexual orientations or gender identities can serve as a starting point. Despite older adults' lower use of ICT compared with younger adults, technology plays an important role in their lives. For example, in a study of 235 older adults (ages 64-104) with diverse living arrangements (e.g., community-dwelling or retirement homes), the majority had access to phones (including smartphones) and computers, using these technologies to stay in touch with family and friends and more than half searched for health and wellness information online (Vroman et al., 2015). Similarly, Erickson and Johnson (2011) found that a significant number of Canadian adults 60 years and older used the Internet for email and research. Moreover, they found that older adults' frequency of Internet use was linked to greater life satisfaction, generalized sense of self-efficacy, and perceived support (Erickson & Johnson, 2011).

Potential Technology Barriers and Benefits for Older Adults

ICT use is sometimes hindered by barriers related to socioeconomic status, attitudes toward technology, and fears or concerns about technology. In a review of literature on ICT use and aging, barriers included lower socioeconomic status, less positive attitudes toward technology, privacy concerns, and interface designs unresponsive to different memory and cognitive functioning (Charness & Boot, 2009). Similar findings emerged from research in the United Kingdom (Selwyn, Gorard, Furlong, & Madden, 2003) and the Netherlands (Slegers, Van Boxtel, & Jolles, 2009). In Gatto and Tak's (2008) study of Internet users 60 years and older, barriers included frustration with the time it took to acquire the skill to navigate the online environment and

frustration with pop-up advertisements and spam. In the same study, however, the most frequently cited benefits of Internet access were the ability to maintain a sense of connectedness and access to online services (e.g., financial services, shopping). In a Swiss study of older adults (Seifert & Schelling, 2018), participants said the Internet was a useful tool that enhanced everyday coping and supported independence.

In examining the impact of involvement in online communities for older adults, Nimrod (2014) noted a number of benefits and barriers. Benefits included a sense of joyfulness and stimulation (e.g., new sensations and excited by ideas), companionship, service, and self-expression. Barriers included aggressive and insulting posts enabled by online anonymity, and not identifying with other older adults online (e.g., mismatch on political beliefs) (Nimrod, 2014). Relevant to our study, research with older adults has shown that perceived benefits and positive aspects of ICT use outnumbered negative aspects (Mitzner et al., 2010). Benefits included access to health information and the ways technology makes work easier and more efficient, and sustains social integration. Thus, despite potential risks, ICT is an important resource for older adults that sustains social integration and access to information.

Health, Later-Life Planning, and Technology

As suggested earlier, older adults often use ICT to access information about health and ways to enhance well-being. One important domain for health and well-being in later life is information about end-of-life care. Later-life health care planning (e.g., living-will, power of attorney) can inform preferences for end of life and avoid unnecessary or unwanted care. People are more likely to have a living-will if they have children, or a family member confidante, or have had informal discussions about end-of-life planning (Carr & Khodyakov, 2007). In a study of personal and social factors associated with end-of-life planning among older adults (65 and older), two-thirds had discussed their end-of-life preferences with others and had an advance directive (Kahana, Dan, Kahana, & Kercher, 2004).

ICT can serve as an important facilitator of end-of-life planning and health decision-making, via its ability to enhance communication and increase access to health information and end-of-life planning resources. A 2016 study by Cajita et al. examined health-related decision-making and Internet use among older adults. Internet use in general, and health-related Internet use in particular, was associated with a greater preference for active decision-mak-

LGBT Older Adults

Although the majority of older adults have similar developmental, social, and psychological needs (Mock, Taylor, Savin-Williams, 2006), older LGBT adults experience unique challenges and needs that shape their experiences with ICT. For example, worse mental and physical health outcomes are commonly found among LGBT adults compared with the general cisgender heterosexual population (Clements-Nolle, Marx, Gutzman, & Katz, 2001; Fredriksen-Goldsen et al., 2014; Graham et al., 2011). These poorer outcomes stem largely from stigmatization and marginalization experienced by those with diverse sexual orientations and gender identities and the psychological toll of concealing a LGBT identity (Meyer, 2003). LGBT adults are less likely to call upon family for care when the need arises and more likely to engage friends, although such caregivers are lesser recognized and supported (de Vries, 2013). As noted by Knochel, Quam, and Croghan (2011), LGBT adults are a significantly-under served and largely invisible population with respect to the planning and provision of aging services (Brown, 2009). Thus, for older LGBT adults, the potential for ICT to enhance quality of life and social integration may be valuable.

Summary and Present Research

ICT offers many potential benefits and challenges for older adults. It may enhance agency and social integration in later life and be a resource for decision-making and later-life planning. To better understand the role of technology in the social integration, well-being, and later-life planning of older LGBT adults, we conducted focus groups with older LGBT adults. Grounded theory methods inform this research (Strauss & Corbin, 2008), an appropriate approach when seeking to understand a relatively unknown or unexplored phenomena. The meaning of technology to older LGBT adults, how it affects their social integration, and the role of ICT in later-life planning were guiding themes for this research.

Method

This study employed focus group methodology (Morgan, 1997). Focus groups rely on the interaction between participants to elicit attitudes and opinions, generating rich contextualized data that would not be obtainable by other methods (Morgan, 1997), and are useful when dealing with minority populations and marginalized or disempowered groups (Hughes & Dumont, 1993; Kitzinger, 1994). The collaborative nature of the focus group environment allows for underlying assumptions, cultural values, and group norms that are a result of a shared experience to come to the surface (Robinson, 1999).

Participants leveraged technology for health-related purposes. Similar to later-life planning, they used online resources to research, plan for, and access health assets. Much of this was done not only through formal channels such as websites like WebMD and various provincial health boards, but also through more informal social networking websites such as Facebook, Xtra, and Prime Timer\$. This use of technology to access information on health was particularly relevant for gay men in this study: In a number of the focus groups, discussion emerged around the impact of HIV/AIDS and how technology such as preventive screening and online information sources had helped to alleviate some of the stigma associated with the disease. "When I was diagnosed 20 years ago it was a death sentence . . . people are beginning to view it differently" (Brad, gay focus group). Participants also used social networks to identify LGBT-friendly resources such as long-term care facilities and physicians. "I'm trying to find a gay-friendly massage therapist because I'd rather go to [a] guy rather than a woman for a massage" (Brad, gay focus group).

Online medical information was of particular significance to the trans women and men. "It's hard to find a doctor that is trans friendly . . . that even knows what it means to be trans" (Michel, trans female focus group). Participants noted a lack of understanding or research about aging as a trans person and the medical impacts of long-term hormone use. As such, social networks where they could chat and share information with similar individuals became very important. A number of trans participants who did not meet the criteria for gender affirmation surgery as outlined by their provincial health policies spoke of using social networking websites to acquire "black market" or "under the table" hormones.

Social Elements

Social elements relate to the establishment and maintenance of personal relationships and social support networks. Social networking websites (i.e., Facebook, Prime Timers, Xtra, Gay Fathers) enabled individuals to expand their social circles, specifically with other LGBT older adults. "Unless you're able to get online it's very difficult to make connections" (Tracy, lesbian focus group). This was particularly relevant for people from places with small LGBT populations who did not have access to a vibrant LGBT community. For them, this virtual community connected them to individuals and community information and in doing so played a role in the expression of their social identities.

Technology had an impact on the development and maintenance of social support networks for older LGBT adults. Participants used cell phones and

"Technology is great if people have the resources" (Ruby, trans female focus group). Having a fixed income and additional costs related to health care (e.g., medications or "transitioning" costs) were the main reasons for this cost sensitivity.

Access and usability also affected LGBT older adults' technology use. Many experienced difficulties in actually accessing technology. Many did not own a personal computer; others noted that the facilities they lived in were not set up for Internet access. Because they did not have access at home they had to go to a public location such as a library or a family member or friend's house. This was further restrictive as many could not or did not drive and relied on public transportation.

Discussion

We found LGBT older adults shared many fears, benefits, social factors, and contextual factors related to the role of technology in later-life planning, social integration, and well-being seen in research on cisgender and heterosexual older adults. Our findings also show the unique challenges in older LGBT older adults' experiences with technology and later-life planning related to sexual orientation and gender identity. Although it is important to consider our findings in relation to the aging population in general, it is vitally important that the unique issues experienced among LGBT adults are accounted for in future work.

Our findings correspond to barriers and benefits found in other research on technology use among older adults, such as privacy concerns and insulting posts that occur in online discussion forums (e.g., Charness & Boot, 2009; Nimrod, 2014). Online harassment was a particular concern for some focus group participants, especially as it related to diverse sexual orientations or gender identities, found in other research on technology use among older adults (Charness & Boot, 2009). Some of the fears or concerns expressed by participants about later-life or end-of-life planning echoed those found in other research. Namely, having confidantes and informal conversations are commonly linked to higher likelihood of making end-of-life plans (Carr & Khodyakov, 2007; Kahana et al., 2004) and the role of ICT in reducing isolation may facilitate these conversations.

Findings from this study about the potential benefits of technology and its role in later-life planning and well-being are consistent with previous research (Wahl et

Interestingly, concerns about stigmatization and isolation, considered unique factors for LGBT older adults (e.g., Clements-Nolle et al., 2001), in many ways amplified the barriers and benefits of technology use. For example, although potentially hostile Internet content is a concern for all older adults, it was particularly so for some of our participants. Similarly, the fears or worries many older adults have about the transition to long-term care may be amplified for older LGBT adults. Reflecting this sense of vulnerability regarding long-term care or other institutions, one participant noted a discontinuity that exists between policy and practice in that LGBT-friendly policies were not always carried out. Thus, despite institutional policies that support LGBT individuals, these policies sometimes do not translate into practice.

Just as typical fears and concerns regarding technology and later-life planning may be amplified among LGBT adults, so are the potential benefits of information technology use. Information technology in general, and the Internet in particular, are acknowledged as uniquely supportive media for LGBT older adults. Information available on the Internet and from online LGBT communities are key resources for understanding identities and creating a sense of community, becoming a form of “safe space” where individuals can be free of ridicule and discrimination. The role of LGBT-focused online communities to find “LGBT-friendly” services and personals websites (e.g., SilverDaddies) for relationships and care support in later life is also relevant.

The insights we gained from LGBT adults reveal not only the similarities and differences between LGBT and other adults with respect to technology use, social integration, and later-life planning but also substantial heterogeneity among LGBT older adults. It is worth noting that, although most participants acknowledged the potential benefits of ICT, some acknowledged variability in access. For some, medical costs, including costs related to transitioning, may make Internet access and computer equipment a lower priority. Trans participants’ also noted unique challenges related to rigid definitions of gender in health service systems and misunderstandings of gender identity.

Limitations

Great efforts were made to recruit a diverse sample of participants, but older non-White, bisexual, and rural LGBT individuals were underrepresented. Although rates of technology use among older adults are increasing, our selection criteria excluded those with no or limited access to technology and cannot speak to their experiences. All participants were comfortable with identifying as a member of the LGBT community, and we do not have insight into the experiences of those who are not “out.” Our findings are not meant to be transferable to all older LGBT populations in Canada; rather, these data

offer important methodological considerations to address in future research in the area of end-of-life decision making.

Practice Implications

Findings have implications for multiple levels of practice and policy that

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