Advance care planning among older gay men living with HIV in Montreal, Canada:

Challenges to *thinking* and *talking* about future care

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Abstract

This qualitative study employed a cross sectional focus group design to explore how older gay men living with HIV, experience, perceive, and engage with advance care planning (ACP). Seven gay men 50+, residing in Montreal, Canada, participated in a focus group that was audio-recorded, transcribed, and thematically analyzed. Findings suggested that social isolation, preoccupations with day-to-day living, and managing disclosures related to sexual orientation and HIV status created barriers to these men's capacities to *think* about let alone *talk* about future care. These findings challenge current conceptualizations of ACP, which position reflection as an individual process that precedes allocating a decision-maker and communicating care preferences. Analyses further revealed that relational connections helped create a space where ACP could occur for participants. Hence, improving the uptake of ACP amongst older gay men with HIV may require interventions that embed such discussions into broader programs aimed at building support and community.

Key words: end-of-life, gay men, HIV, advance directive, aging, care planning, palliative care

Introduction:

Advance care planning (ACP) is a process whereby people with progressive life-limiting conditions reflect on, communicate and sometimes document their values, wishes, and preferences for future care including end-of-life care (Howard, Bernard, Tan, Slaven, Klein& Heyland, 2015; Sinclair, Oyebode & Owens, 2016; Sudore & Fried, 2010). ACP aims to ensure persons with life-limiting conditions remain at the centre of their own care by providing avenues for communicating care preferences to family/close friends, legally appointed decision-makers and health providers, when capacity for reflection, communication, and decision-making is present (Howard et al., 2015; Sudore & Friend, 2010). While ACP can include the documentation of advance medical directives (e.g. non-resuscitation and non-intubation orders) it also encompasses reflections and discussions about values and preferences such as views about dying alone, spiritual beliefs that may provide comfort at EOL, and values related to quality of life/quality of care which can be used by health proxies to inform in-the-moment care decisions (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014).

Evidence documenting the positive impacts of ACP on end-of-life (EOL) care is growing (Ashton, Roe, Jack, & McClelland 2016; Black et al., 2009; Brinkman-Stoppelenburg, Rietjens & van, 2014; Chen et al., 2015; Elliot, Gessert & Penden-McAlpine, 2009; Poppe, Burleigh & Banerjee, 2014; Radwany et al., 2014). Positive EOL outcomes associated with ACP include congruence between peoples' wishes and care provided; lower rates of unnecessary hospitalization at EOL; reduced stress, depression and anxiety amongst families/close friends; and improvements in feelings of autonomy, control, and care satisfaction for all parties (Bischoff, Sudore, Miao, Boscardin & Smith, 2013; The Commonwealth Fund, 2014; Detering, Hancock, Reade & Silvester, 2010; Gott, Ibrahim & Binstock, 2011; Ke, Huang, O'Connor & Lee, 2015; Litzelman et al., 2017; Lum et al., 2016; Robinson et al., 2012).

While there is a growing body of literature documenting the positive effects of engaging in ACP for older persons with health-related challenges, recent work has documented low uptake of ACP amongst marginalized groups such as racial and ethnic minority older adults (Hong, Yi, Johnson, & Adamek, 2018), older adults living in poverty (Harrison, Adrion, Ritchie, Sudore &

Smith, 2016) and lesbian, gay, bisexual, and transgender (LGBT) older adults (Hughes & Cartright, 2015). Common barriers to engaging in ACP for these populations include power inequities and mistrust of health care systems/providers, culture preferences for non-disclosure of prognosis, and preoccupations with day-to-day needs and realities, particularly in the context of poverty and/or resource scarcity (Zikovic, 2018).

Some research has begun to document the issues LGBT older adults encounter with ACP (de Vries et al., 2019; Harding, Epiphaniou, & Chidgey-Clark, 2012; Lawton, White & Fromme, 2014; Marsack & Stephenson, 2018). Social isolation and loneliness[i] have been identified as potential risk factors, limiting both the initiation and the activation of ACP within this population. Additionally, the predominant North American focus on biological family (i.e. spouses and adult children) can result in the alienation or perceived exclusion of non-kinship-based support systems as targets of caregiver interventions and outreach. These barriers may also contribute to reduced engagement with ACP within the LGBT community (Cartwright, Hughes, & Lienert, 2012; de Vries et al., 2019; Wilson, Kortes-Miller & Stinchcombe, 2018). Yet, precisely because many systems still prioritize biological or ‘traditional’ family forms, allocation of decisional capacity to a preferred health proxy is of particular relevance to LGBT older persons who may not elect to allocate decisional capacity to an individual outside of theibiological family members (Lawton et al., 2014). While this biological/legal focus can alienate all persons whose family forms do not include legal-partnerships or biological kin, it may be particularly alienating for those who already face other forms of marginalization, such as LGBT older adults (Brotman & Ferrer, 2015) and ethnic and racial minority LGBT communities (Ryan, Brotman, Baradaran and Lee, 2008).

One community within the broader LGBT population whose engagement with ACP warrants research and practice attention is the population of gay men living with HIV (Stein & Bonuck, 2001). Gay men living with HIV are at a heightened risk of developing comorbidities known to accelerate aging and limit life span such as cardiovascular disease, chronic kidney disease, diabetes, cancer, and liver disease (Cahill & Valadéz, 2013; McMillan, Krentz, Gill & Hogan, 2018). Yet gay men living with HIV experience unique barriers to ACP engagement because of their fears of managing the stigmatizing attitudes that may accompany their disclosure of their HIV status (Wallach & Brotman, 2019) and/or their sexual orientation (Harrison, 2006) to those who may otherwise be identified as partners in these discussions. For example, Emlet (2006) who conducted a study that included older gay men living with HIV reported that almost all those interviewed had experienced HIV-related stigma and, more than half did not disclose HIV status to family or friends. Further, older gay men are at risk for social isolation especially when considering the fact that these men may have survived myriad deaths of close friends and partners in the early years of the HIV/AIDS pandemic, further compromising their social networks in old age, and potentially impacting their views on EOL care (Cahill & Valadéz, 2013; Erlandson et al., 2012).

Since over half of persons living with HIV in North America are 50+, and older gay men with HIV face unique challenges associated with intersectional stigma related to HIV status, sexual minority status , and age, examining access to ACP for older gay men with HIV is both timely and warranted (de Vries et al., 2019; McMillan et al., 2018; Senate Special Committee on Aging, 2013).

This study begins to address a critical gap in our understanding of how to improve access and uptake of ACP by examining how the intersections of age, sexual orientation, and HIV status work together to shape perceptions of and experiences with ACP for seven gay men, 50+ living in the city of Montreal, a major urban centre in Canada. Part of a larger pan-Canadian study (iCAN-ACP) focused on increasing engagement, impact, and access to ACP for older marginalized adults (You, et al 2017) this study aimed to answer the following research questions: (1) what reactions do gay men aging with HIV express when reflecting on ACP engagement? (2) how, if at all, have gay men aging with HIV engaged with different aspects of ACP? (3) what barriers do gay men aging with HIV encounter attempting to reflect on and/or communicate future care concerns and finally (4) what may improve access to and uptake of ACP from the perspective of older gay men living with HIV in a major urban city?

Materials and Methods

This study used a focus group approach to elicit the experiences and perspectives of ACP of a group of older gay men living with HIV. A focus group approach has been identified as a qualitative methodology which can encourage persons from traditionally marginalized communities to express their experiences in a comfortable and safe environment (Allen, 2006). Since stigma associated with marginalization and depression can lead to social isolation and a sense of alienation from others who may have had similar experiences, a focus group approach can create opportunities for participants to identify shared experiences, and create a space in which participants can feel validated in order to facilitate disclosure in a way less possible in one on one interviewing (Allen, 2006). Little direction is offered on the number of focus groups required to answer a research question (Carlsen & Glenton, 2011). Given the exploratory nature of the study, the challenges recruiting participants from marginalized groups, and our interest in testing the usefulness of our focus group design to uncover the sensitive nature of the subject matter, we elected to focus our energies on organizing one rich focus group.

The focus group was co-facilitated by two members of the research team. Both facilitators openly disclosed their identities as non-seropositive gay men in their mid to late thirties. Openly positioning themselves in relation to the topic was done in order to build trust with participants as well as acknowledging the importance of shared identity and shaping group dynamics (Rodriguez, Schwartz, Lahman & Geist, 2011). The co-facilitators used a semi-structured interview guide aimed at exploring participants' views on and experiences with ACP. The interview guide also inquired about the relevance of a workbook (Your Conversation Starter Kit) designed to support ACP discussions (see https://theconversationproject.org/wp-content/uploads/2016/09/TCP_NEWStarterKit_Writable_Sept2016_FINAL.pdf). This component of the project will be reported in a future paper addressing the usability of this and selected other ACP workbooks among marginalized older persons examined in the broader study.

Achieving saturation was an important component of data collection given the data were derived from one focus group. Hence probes, and additional questioning were used, as needed, to ensure that a full understanding of participants' perceptions and experiences was achieved (Legard, Keegan & Ward, 2003). As a testament to participants' engagement and the complexity of the topic, deliberations related to views on ACP lasted two and a half hours.

The research was conducted in accordance with the standards of the Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans (2018). Data collection procedures were approved by the Office of Research Ethics Board at McGill University.

Recruitment took place through community agencies via social media (e.g. Facebook, listservs of community groups supporting gay men or persons with HIV), and word of mouth. Organizations working specifically with older gay men living with HIV who agreed to support recruitment were provided with a flyer for distribution describing the project and its objectives. People interested in participating were asked to email or call the research coordinator. The recruitment materials emphasized the voluntary nature of participation which was reiterated when potential participants contacted the research coordinator to express an interest in the study. Inclusion criteria were identified as: (1) being 50+ (consistent with previous research; e.g., Emlet, O'Brien & Fredriksen-Goldsen, 2019); (2) identifying as a gay man living with HIV; (3) ability to communicate in English or French and (4) living with one or more chronic health conditions including those related or unrelated to their HIV status. This latter criterion was, in part, driven by the focus of the funding agency. Signed written consent was obtained on the day of focus group participation. Participants received a $25.00 gift card for their participation in the focus group.

Although both French and English speaking participants were recruited, the focus group was facilitated in French, because all participants had the capacity to communicate in French, and French is the majority language for service provision in Quebec. A total of nine participants expressed an initial interest in participating of which seven attended and participated in the focus group. While all nine potential participants met the eligibility criteria of the study, one was not able to attend due to illness and the second could not be reached after an initial phone discussion to explain the nature of the study.

The deliberations from the focus group were audio-recorded, transcribed verbatim and thematically analyzed in six steps (Braun & Clarke, 2006). In the first stage of analysis the first author began the process of familiarization by reading the focus group transcript thoroughly, and noting observations and meanings in memo form. In the second stage of analysis, these observations and meanings were discussed amongst all researchers who collectively identified initial codes thought to broadly capture participants' thoughts, experiences and reactions to ACP. We followed an inductive approach identifying patterns and then developing codes that we felt represented the meaning expressed by participants (Marshall & Rossman, 2006, p. 159). Codes such as participants' concerns about future care, the challenges of aging with HIV, and beliefs and experiences with ACP were developed at this stage and subsequently matched with data extracts by the first author. We extracted large chunks of data (typically two paragraph) to ensure that the context of participant expressions were preserved.

In the third stage of the analytic process, initial codes and extracted data were reviewed and discussed by all researchers who collectively reflected on the connections and patterns within and between codes. This process of searching for themes resulted in the development of three themes thought to capture a comprehensive story: (1) social isolation; (2) managing disclosure and (3) living in the moment. In the fourth stage of the analytic process, the first author produced a draft report of the findings framed around three broad themes to further examine the extent to which these potential themes both answered the research questions and provided a cohesive characterization of the focus group discussions (Neuendorf, 2019). In the fifth stage of analysis the second and third authors reviewed the draft report of the findings, juxtaposing the themes identified with the original transcripts. This process was undertaken to develop a more detailed analysis of each theme while also exploring for accuracy, comprehensiveness and redundancy. At this stage of the analytic process *uncertainty* arose as a central concept because it appeared to represent a common thread underlying all three themes and provided a more nuanced lens through which to appreciate both participants' understandings of and experiences with ACP. Hence in the sixth and final stage of analysis, the preliminary three themes were adapted and expanded though the lens of *uncertainty*. This resulted in the development of four themes thought to ”weave together the analytic narrative”(Neuendorft, 2019, p. 6) by presenting the way in which *uncertainty* operated at personal, relational, and structural levels. After this final stage, all selected French extracts were translated by one member of the research team and cross-checked by two others to ensure the essence of the original statements were maintained. Our capacity as a team to analyze the data in its original language functioned to ensure that the meanings expressed by participants closely aligned with the interpretations reported by the researchers (van Nes, Abma, Jonsson & Deeg, 2010). All participants have been ascribed pseudonyms so that their personal thoughts and experiences can be followed.

Results

Participant Sample

Seven older gay men living with HIV participated in the focus group. They ranged in age from 55–73 years old, with a median age of 62. Participants had been living with HIV for between 17 and 29 years (median of 25 years) and reported comorbidities such as cardiovascular disease, kidney disease, respiratory issues and cancer. Five participants lived alone. Four were single, two were divorced and one was partnered. Two participants identified themselves as belonging to an ethno-cultural minority group (Latino and Haitian). Five participants reported an annual income of $30,000 (CND dollars) or less, and four had experienced financial struggles throughout their lifetime. Six participants were renters and three had lived in their current rental accommodations for less than a year. The low income and precarity faced by our participants resembled that which has been reported in the literature for gay men living with HIV (Emlet, Fredriksen-Goldsen & Kim, 2013; Hogg et al., 1994; Joyce, Goldman, Leibowitz, Alpert, & Bao, 2005). Regarding prior engagement with ACP, two participants had completed non-resuscitation orders and one had appointed a health proxy in the event of incapacity. However, as can be seen from the findings below, these small steps were rarely accompanied by reflections and conversations about more global care preferences, fears and concerns.

Findings

Analysis of the data revealed that most participants lived in the liminal space between knowing future planning is "a good idea" "important" and "worthwhile" while also living with avoiding planning by "pushing thoughts about the future to the back of [their] mind[s]" ("Pierre").

Underlying the tensions between endorsing the benefits of ACP and questioning the personal relevance of ACP was a general sense of uncertainty about personal, relational, and structural realities that exist when aging with HIV.

The findings presented below are framed around four key themes: (1) *isolation fosters uncertainty regarding who to discuss future care with*; (2) *living in the moment to manage the uncertainties of life and health*; (3) *managing the uncertainty of disclosure creates a challenge for planning ahead*; and (4) *relational connections help to manage uncertainties and provide avenues for discussing future care*. Together these themes highlight the ways in which uncertainty and precarity function to create challenges to ACP engagement for older gay men living with HIV. They further illuminate how relational connections can help to manage uncertainties and create a space where future care discussions can occur.

Isolation fosters uncertainty regarding with whom to discuss future care

While the focus group discussion began by asking the types of future care issues men with HIV considered important to consider, very quickly these reflections elicited feelings of being alone with these concerns and lacking someone with whom to discuss these issues. As one participant stated*, "*I did not plan anything. I find that in my situation it, it would be necessary that I take some actions, but I have not found the right person to confide in" ("Hasan"). The importance of having someone with whom one feels connected to motivate and support reflecting and planning for the future was affirmed by other participants as identified in the following statement, "I was tempted to do it, but, uh, I do not know, uh, what with held me, uh ... [laughing] I do not know. It's because I have no friends and no strong family ties" ("Jacques"). A third participant expressed feeling "hidden" ("Theo") depicting a strong sense of feeling unseen, forgotten, and left behind.

Even those who had children and/or had selected someone to act as their substitute decision maker expressed feelings of isolation and the lack of a trusting person with whom to discuss future fears, concerns and wishes. A participant who had ascribed decision-making authority to his son noted this circumstance when stating:

> when my son comes to see me he asks me 'who is going to have your things when you die?' and I say 'I have not planned that yet 'and it struck me he asks me about this a lot instead of asking me 'how are you? How is your health?' ("Jacques")

His comments serve as a reminder that isolation may force someone to allocate a decision maker for pragmatic planning even if a relational base that fosters the expression of emotional issues is absent.

In sum, although planning for and thinking about future care was important to participants, isolation was identified as a primary barrier in engaging in these processes of reflection and conversation. Feeling 'hidden' and alone, most elected to push such thoughts to the side and carry on with day-to-day challenges. Importantly many participants suggested this isolation was becoming a growing issue for them as they aged.

Living in the moment to manage the uncertainties of life and health

The combined precariousness of living with chronic health concerns, social isolation and uncertain financial stability worked together to preoccupy many of the participants with day-to-day challenges. One participant preoccupied with day to day worries about health, functional decline and finances expressed**:**

> For me, it's more important to worry about my health now, to live fully now. What will happens to me after, I don't even think about it, but I think about all that is happening to me right now, and that worries me…. Since I am not working any more, I don't know if I am going to be able to manage all of my expenses. Will I have to cut off the cable, the phone? ("Jacques").

Others spoke of the ongoing efforts it takes to manage their current health in a siloed system forcing them to move back and forth between specialists such as nephrologists and cardiologists who know little, if anything, about HIV and clinics wherein their HIV is managed.

While most affirmed that preoccupations with living in the moment precluded them from planning ahead, future worries and concerns nonetheless seeped into their thinking. Faced with the uncertainties of the day to day and having no one with whom to share and problem solve these worries however, led participants to push aside these thoughts and concerns. One participant experiencing this tension states:

> I can still drive so I can go wherever I want, but the day I can no longer drive for whatever the reasons, what am I going to do? For me, this is one of my big worries, but then I say to myself 'Well. I'll worry about that later. I'll see when it happens. Why should I worry about it before then?' ("Ulysse")

Another participant who thinks about his own functional decline because he lives beside an aging neighbour stated:

> It's not like I don't think about it or worry about it at all. My neighbour's 79 and he has bad lung issues similar to mine and he can't stand up or go to the bathroom without getting out of wind. He's in really bad shape and it's gotten worse… so it's a constant reminder. ("Pierre")

A number of participants had engaged in the emotional work of planning for their future end-of-life care once before, during the early years of the AIDS crisis in the late 80's and early

90's. For some it took years before they allowed themselves to believe they may not die. This type of experience may have also contributed to a tendency to live for today rather than think about the future. As one participant stated:

> In 1992, I thought I would only live for four years. That's twenty-six years ago now. When you think you are at the end of your life, it takes two or three years before you realize 'Well, [maybe] you will not die.' ("Ulysse")

In sum, day-to-day challenges were prevalent and often consuming for many of these participants making thinking about the future more than they could themselves manage. Despite their best efforts, worries about future care seeped into their minds on occasion reminiscent of experiences in the early years of the AIDS crisis. However, feeling isolated and alone, these seemingly unresolvable concerns were pushed to the side rather than brought to the forefront, obstructing the process of future planning.

Managing the uncertainty of disclosure creates a challenge for planning ahead

Managing disclosures was a regular part of participants' lives. Hence, choosing when and with whom to share one's sexual orientation, HIV status, or both was a source of regular tension for many. One participant who observed how disclosures around sexual orientation could lead to alienation from family shared, "I know one friend who told his brother [that he was gay]. His brother never invited him over to eat again once he disclosed he was gay… so what do you think about talking about HIV?" ("Elliot"). Another participant who noted that preserving social connections could mean hiding one's HIV status stated:

> If people don't know you are HIV positive and in your head it is clear that the family will reject you if you share this news and they are the only ones related to you then you'd better [not disclose] ("Jacques").

These realities made engaging in open discussions about future health concerns with family and friends highly risky and tenuous.

Given that most participants had spent their lives making decisions about when and with whom to share their sexual orientation and HIV status, preparing to select a legal decision-maker in the event of incapacity or deciding to less formally discuss wishes for future care became much more complex than thinking about a person who would be able to follow through on one's wishes. Rather it also meant thinking through how such individuals may react to the disclosures that needed to precede such discussions. As one participant states:

> There are specific things you ask yourself when you think about the people with whom you may want to have a conversation with. Do they know you're gay? Do they know you are HIV positive? If they don't know then there is a lot of information that they do not have. ("Ulysse")

Managing disclosure was also evident when thinking about services that may be required for future care. Here, the realities of discrimination around sexual orientation and HIV status meant that transparency may lead to being rejected by needed services. One participant who conducted some field research on behalf of an organization he was working for described calling residences disclosing his HIV status and asking about potential accommodation there. After setting up a meeting to view the accommodation he was told that "there is no space [for him]." Suspecting his HIV status and not lack of vacancy he explains, "they were afraid…. afraid for the other residents" ("Ulysse"). This example highlights the systemic barriers associated with planning ahead for older gay men with HIV.

Relational connections provide avenues for reflecting on and discussing future care

To combat isolation, loneliness and social rejection, some participants took comfort in connecting with community organizations offering opportunities to connect with others who were also living and aging with HIV through lunch programs and activities like Tai Chi, gym classes, and painting. These venues were described as extremely meaningful to forge connections as one participant stated, “I hang out with all my group and we are all gay, all with HIV, so we could talk about anything” (“Theo”).

For some, group connections within organizations were venues wherein engaging in discussions regarding future care and concerns could be possible. As another participant also connected with a group for older adults with HIV states:

> During the last year we had an information session on writing your will and I plan to reach out and make sure it’s all understood…. I don’t really have anything valuable to pass on… maybe my guitar but I can give that to X organization (“Pierre”).

For others however, relational connections had not evolved from these organizations. As one participant notes, “I think we are pretty well informed [about what is available] and the organizations are very welcoming. The problem is more relational I think… friendships, family stuff like that” (“Hasan”).

The focus group itself appeared to be a forum wherein individuals began to feel comfortable discussing concerns that had been weighing on them. For example, as participants gained comfort and connection with one another they began reflecting on and expressing preferences for location of death, “I’d either like to stay in my apartment until I die or move into an HLM [rent geared to income apartment] if I get accepted” (“Pierre”); family involvement at end-of-life, “I personally want to die alone” (“Jacques”), “I would like to have my loved ones around if it feels comfortable for them but if they are not comfortable with it then I do not want them” (“Ulysse”); preferences for more/less medical involvement, “I will not fight for survival I prefer [dying] to suffering” (“Hasan”); and concerns about future losses, “right now I can still drive my car and I can come into the city whenever I want to but the day I am no longer able to drive for whatever reasons, what am I going to do in [current location]… that is one of my big worries (“Ulysse”). Hence the process of support offered by being amongst a group of individuals with a shared history and common concerns regarding, health, social support and aging appeared to provide a space for reflections to be shared.

One person expressed his appreciation for coming to the group and the realization that planning ahead would be a gift to his siblings should he die before them. He states:

> And they [sisters] probably expect 'oh we'll have to go and deal with all of his shit and pay for cremation and…' No, I want them to be happily surprised. So yeah. It's uh, I'm glad I came and I'm gonna take steps to move forward on that. ("Pierre")

Once again, this quote illuminates that personal connections with others can serve as a motivating factor in activating ACP particularly when it comes to post mortem planning. At the same time, it reveals some of the tension involved in such connections.

Discussion

Our focus group revealed that older gay men with HIV recognized that ACP was important, a view which resembles that of many older adults in North America (Conversation Project, 2015). However, our findings also revealed myriad challenges blocking participants' capacities to reflect on, discuss and/or document their concerns for their future end-of-life care. More specifically, the barriers to ACP engagement included a limited circle of friends and families with whom to discuss such issues, the precarities of day-to-day living, and the tenuous balance between withholding disclosures of sexual-orientation and HIV status in order to preserve relationships. It is notable that according to participants, such challenges not only interfered with capacities to *talk about* their future care concerns, but also created barriers to *think about* such issues. The precarity and disadvantage that shaped the lives of our participants seemingly challenged their belief that the future could be imagined and hence interfered with such reflections (Zivkovic, 2018). Interestingly, Pang, Gutman & de Vries (2019) reported similar findings with their focus group research with transgender older adults.

Our findings are consistent with the work of de Vries and colleagues (2019) who noted the common expressions of loneliness and isolation amongst LGBT older persons (and especially gay men) and the barrier this created for engagement in end-of-life discussions and planning, among a host of health and related social issues (de Vries, 2013). Our findings also affirm that of Emlet (2006), who identified that disclosure of HIV status to family and close friends is of high concern to older men who fear losing the limited support they have. Expanding on these works, our findings illuminate that the realities of guarding identities which serve to distance individuals from potential supports (Meyer, 2003) and the limited social networks available to begin with, not only precluded open dialogue about future care issues, but also interfered with these men's capacities to 'talk to themselves' about these issues (de Vries et al., 2019). Reflections about end-of-life may have been particularly complex for this group of individuals, as many had witnessed the traumatic and painful loss of close friends, partners and family. And, many men in similar situations lived at least part of their earlier lives believing they were near to death. Reflecting on one's own death, again, as well as recalling the often-disturbing end-of-life processes of their friends and others in the early years of the HIV crisis, may make the notion of reflecting on one's own death that much more challenging.

Current conceptualizations of ACP position reflection as a first step towards allocating a decision-maker and communicating wishes and preferences for future care—both verbally and if desired, in writing (Sudore et al., 2017). Workbooks, videos, and other materials such as those being tested in our larger project have been developed and widely disseminated to encourage this initial reflection (Bridges et al., 2018). While such strategies may reduce the stigma associated with discussions about death and dying, our findings suggest that such approaches may be ill-suited to older gay men with HIV whose avoidance of such reflections is grounded in life long experiences of discrimination, exclusion, social -isolation/stigma, and loneliness (deVries, 2015; Furlotte & Schwartz, 2017).

Importantly, our findings further illuminated that social connection appeared to support the creation of a space where future worries could be identified and openly discussed. This is an important initial step and may answer Erlandson and colleagues' (2012) call for improving the uptake of ACP for all adults living with HIV, noting an uptake of less than 50% even amongst those well connected with health systems. In the context of our focus group, participants expressed preferences related to their future care should their function and health begin to deteriorate.

The broad and comprehensive implications of social isolation for ACP are indeed impressive as are, by extension, the integrating potential of social connection. For example, our work suggests that building networks of support for this group of men may be the first step towards improving access to ACP. Increasing the uptake of ACP amongst older gay men with HIV may require interventions that embed such discussions in a broader program aimed at building support and community. Such efforts are afoot and seen in groups such as Let's Kick ASS (https://letskickass.hiv), a grassroots movement for long-term survivors of HIV encouraging visibility, social connection and action (challenging AIDS Survivor Syndrome, ASS) alongside other such community-based efforts for older LGBT persons.

In response to a need identified in our previous research for a place to gather ACP and end-of-life information in an LGBT-affirmative environment as well as to facilitate virtual community building, a web-based resource (Beringer, Gutman, & de Vries, 2017) has been developed by our team (https://www.sfu.ca/lgbteol.html). A face-to-face version of the same was created in PALS: Planning Ahead for LGBTQ Seniors (https://palsinthedesert.com). This study on aging men with HIV suggests that while such LGBT affirmative resources may serve those who have some meaningful ties and connections others may require a wider program of support within which to engage with such materials.

Study Limitations

This study should be viewed in light of two important limitations. First, the study relied on a small sample of self-selected men in one Canadian urban centre. These circumstances limit transferability of findings to other older gay men living with HIV who reside in different jurisdictions. Second while some have documented the divergent experiences of older gay men who have aged with HIV and those that acquired it at old age, our small sample size precluded us from exploring such differences. For example, it is possible that those who survived HIV in the 80’s and 90’s hold a different perspective on life, death and end-of-life that those who have acquired it later (Cahill & Valadéz, 2013). Other important comparisons such as differences between Francophone and Anglophone participants, or between racial and ethnic minority and non-minority participants could not be conducted due to our limited sample. Future research should examine the extent to which obstacles for reflection are influenced in part by such circumstances.

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[i] Social isolation can be defined as the limited or lack of social contact experienced by an individual. Loneliness, is an outcome of social isolation, when there is a gap between the existing amount and quality of social contact when compared with that which is desired by the individual (Brotman et al., 2019).