

# Advance care planning among older Canadians amid the COVID-19 pandemic: a focus on sexual orientation

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Palliative Care & Social Practice

2021, Vol. 15: 1–14

DOI: 10.1177/  
26323524211019056

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## Abstract

**Objectives:** The COVID-19 pandemic has led to death and hardship around the world, and increased popular discourse about end-of-life circumstances and conditions. The extent to which this discourse and related pandemic experiences have precipitated advance care planning (ACP) activities was the focus of this study with a particular emphasis on sexual orientation.

**Methods:** A large, national online survey was conducted between 10 August and 10 October 2020 in Canada. The final sample of 3923 persons aged 55 and older was recruited using social media, direct email, and Facebook advertising and in conjunction with community groups. Women comprised almost 78% of the sample; just more than 7% of the sample identified as lesbian, gay, and bisexual (LGB). Measures included demographic variables and a series of questions on ACP, including documents and discussions undertaken prior to the pandemic and since its onset.

**Results:** Descriptive analyses revealed few gender or sexual orientation differences on documents and discussions prior to the pandemic; since its onset, LGB persons have completed or initiated wills, powers of attorney, advance directives, representation agreements, and have engaged in ACP discussions in greater proportion than heterosexuals. Logistic regressions reveal the increased likelihood of pre-pandemic ACP engagement by age, gender (women), and education; since the pandemic onset, gender, education, and sexual orientation were predictive of greater ACP engagement. Care discussions were more likely undertaken by women and LGB persons since the pandemic most often with spouses, family, and friends, especially among LGB persons.

**Discussion:** Gender roles and previous pandemic experiences (HIV/AIDS, in particular) are implicated in this pattern of results; opportunities for educational interventions are considered.

**Keywords:** sexual orientation (Lesbian, Gay, Bisexual), gender, Advance Care Planning, HIV/AIDS, Canada

Received: 9 December 2020; revised manuscript accepted: 30 April 2021.

## Introduction

Advance care planning (ACP) has received increasing attention over the past several years in Canada, perhaps associated with the discussion around federal Bill C-14, the Medical Assistance in Dying Act which passed into law in 2016.<sup>1</sup> ACP is an integrative process wherein individuals, of all ages and

conditions of health, are encouraged to reflect on, document, and communicate their values, wishes, and preferences for future care, including care at end of life.<sup>2</sup> ACP has a more immediate relevance for those with life-limiting conditions and offers structure for the consideration and communication of care preferences to loved ones and caregivers.<sup>3</sup>

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In this article, we examine the extent to which the COVID-19 pandemic has influenced ACP actions and discussions among older adults: those at the greatest risk of COVID-19<sup>4</sup> illness and death and those most addressed in news and policy decisions. We also focus on lesbian, gay, and bisexual (LGB) persons, given their relatively recent and traumatic history with the HIV/AIDS pandemic and our assumptions that such histories manifest in their experience of COVID-19, and ACP. Specifically, we examine the extent of ACP document completion and revision and discussion engagement by older LGB and heterosexual women and men in Canada, both before and since the onset of the COVID-19 pandemic.

### *ACP in Canada*

As in other countries, ACP in Canada is about conversations with family and/or friends, and ideally with healthcare providers about one's beliefs, values, and wishes for chronic and end-of-life care. This information may be conveyed in a written record or video and/or in a set of documents that include the name and contact information of a temporary substitute decision-maker(s) and medical treatments that one would or would not wish. The Canadian Hospice and Palliative Care Association<sup>5</sup> has developed a Pan-Canadian Framework for Advance Care Planning, building upon a 2012 framework supported by Health Canada. It was an enormously challenging task given that ACP documents have varying names and legal standing across the 10 provinces and 3 territories that comprise the country. It was, however, considered a necessary task: few (about 17%) Canadians have made any structured plans for their future care and only about half of all Canadians have engaged in any ACP.<sup>5</sup>

Teixeira and colleagues<sup>6</sup> reported on the general experience of Canadians (aged 18 to >65 years) with ACP. Consistent with the findings above, they found that few Canadians (16%) knew the term 'Advance Care Planning', and slightly over half (52%) of respondents had engaged in any discussions with family or friends about healthcare treatment preferences in the event that they became too ill or injured to speak for themselves; only 10% had ACP discussions with healthcare professionals. In all, 47% of respondents reported that they had designated a person to be their healthcare decision-maker in the event of incapacity and 20% had a written advance care plan document. In the analyses by Teixeira and

colleagues,<sup>6</sup> age was consistently and positively associated with all ACP outcomes; education was positively associated with both knowledge of ACP and written plans; gender (women) and income (higher) were associated with having discussed ACP with family or friends and with an overall sum score of ACP behaviors (summing across the five domains questioned). These findings highlight some of the social determinants of ACP among Canadians, consistent with much previous research from other cultures<sup>7</sup> and countries.<sup>8</sup> Sexual orientation, we argue, needs increasingly to be seen as an important constituent of these social determinants of ACP.

### *ACP and LGBT*

For lesbian, gay, bisexual, and transgender (LGBT) persons, end-of-life attitudes and understanding typically have been framed around the history of HIV/AIDS<sup>9</sup> as well as the related experience of stigma/discrimination.<sup>10</sup> LGBT persons, and gay and bisexual men in particular, have been, and continue to be, disproportionately affected by the HIV/AIDS epidemic. Many within the older LGBT community cared for and grieved the deaths of more than 330,000 gay men in the United States who have died from HIV/AIDS since the 1980s.<sup>11</sup> Wight and colleagues<sup>12</sup> found, in their sample of more than 200 gay men aged 44–75 years, that almost one-quarter of the men had lost 15 or more friends to AIDS. On the one hand, having witnessed and frequently participating in so many HIV/AIDS deaths, often with inadequate and stigmatizing medical care further traumatizing both patients and caregivers, LGBT persons may have a more pressing awareness of the need for ACP.<sup>13</sup> Consequently, LGBT persons, and perhaps gay and bisexual men especially, may be better prepared, both for life in a pandemic and for ACP. On the other hand, LGBT older persons have lived lives characterized by stigma, discrimination, neglect, and invisibility,<sup>14</sup> presaging a reticence and even apprehension to think about future care. Research has supported this association,<sup>15</sup> chronicling the legacy of LGBT disenfranchisement on ACP, given its often heteronormative framing, and their often poorer health and unmet unique needs.<sup>10</sup> These are often exacerbated by the demographic circumstances of LGBT later lives: greater rates of singlehood, greater rates of living alone, and lower rates of having children, all of which implicate restricted caregiver access and greater reliance on healthcare systems.<sup>16</sup> Stinchcombe and

colleagues<sup>17</sup> note the fear of further discrimination as a factor influencing decisions about health-care combined with, and perhaps resulting in, an overall lack of knowledge and preparation for end of life among LGBT older adults.

The former interpretation (i.e. the legacy of HIV/AIDS) suggests a greater likelihood of LGBT persons having engaged with ACP; the latter (i.e. a lifetime of stigma and neglect) suggests a lesser likelihood. Some research has identified the pivotal role of context in mediating these contrasting predictions of ACP engagement by older LGBT persons. The MetLife study,<sup>18</sup> for example, found that LGBT boomers were significantly more likely (than were boomers in the general population) to have completed a variety of ACP documents (even as these document completion rates reached a maximum of about 40%). It was suggested that these relatively higher rates were an adaptive response to stigma, a type of positive marginality<sup>19</sup> resulting from the denial of such rights and exclusionary policies around marriage.

de Vries and colleagues<sup>20</sup> tested this hypothesis more directly with a national sample of almost 800 LGBT boomers. They compared the completion of a variety of ACP documents by LGBT boomers who lived in US states where same-sex relationships were recognized and those who lived in states where those relationships were not recognized. They found that LGBT boomers living in a state that does not recognize same-sex relationships was associated with being *more* likely to have completed these documents, with differences of about 10 percentage points. It is as if the lack of recognition, this sociopolitical context, spurred these boomers into action.

It is important to note that Canada and the United States have a mostly shared history of LGBT inclusion and rights, though Canada has advanced these issues more quickly and fully than the United States. Canada, for example, amended the Canadian Human Rights Act in 1996 to include sexual orientation as one of the prohibited grounds of discrimination<sup>21</sup> and legalized marriages between same-sex couples in 2005, the fourth country in the world to do so and a decade before the United States. Still, the formative experiences of today's older LGBT persons have been comparable to those in the United States and are characterized by a sociopolitical context of denial of rights, exclusion, and stigma.

### *ACP and the COVID-19 pandemic*

The COVID-19 pandemic may be seen as a factor spurring individuals, across sexual orientations and gender identities, into ACP action, a primary assumption and interest of our research. As of 9 March 2021, the COVID-19 pandemic has resulted in more than 2,621,000 deaths worldwide<sup>22</sup> and many times that the number of people have fallen ill to varying degrees. There are myriad consequences of this pandemic in addition to the distressing number of deaths and health tolls, including business, economic, cultural, social, personal, and interpersonal effects.<sup>23</sup> Given the relatively recent experiences of LGBT persons with the HIV/AIDS pandemic (described above), both in disease exposure/prevalence and in the associated stigma, it may well be the case that these consequences are heightened for them.

The first case of COVID-19 was confirmed in Canada on 25 January 2020 attributable to travel outside of the country; by early March, the first case of community transmission in Canada was documented in the province of British Columbia. Shortly thereafter, provinces issued states of emergency (the exact date varying from province to province) with restrictions on social gatherings and encouraging the use of masks. The Quarantine Act on 25 March 2020 mandated that all inbound travelers self-isolate for 2 weeks.<sup>24</sup>

Older adults and those with preexisting medical conditions were identified early in this process as particularly vulnerable to physiological effects of the virus, and public health messages were especially targeted to them. News stories of older adults were similarly numerous and prominent, including stories from Canadian nursing homes where 80% of the deaths have occurred<sup>24</sup> amid reports of overwhelmed, poorly trained, and ill-equipped staff and facilities. Stories of respirator use and demand, invasive interventions, do-not-resuscitate orders, and final wishes dominated evening newscasts speaking, both directly and indirectly, to the core issues of ACP. This attention had the effect of both raising public awareness of ACP and revealing some of the potential barriers to engagement in the process (e.g. trust in the medical system).<sup>25</sup> Although these are data from the United Kingdom, there are valid reasons to suspect similar responses in Canada, including, for example, the universal access to health-care in both countries (even as administered differently).

### *Our study*

The central questions of the research reported here are framed by the literature reviewed above: Has ACP increased in the time since the onset of the pandemic, and if so, are these increases seen across sexual orientations? Given the increase in public awareness in general, and given the previous research linking sociopolitical context to ACP document completion among sexual minority persons, we hypothesize the following:

1. Respondents will report that they have increased their activities of ACP (i.e. document preparation, care discussions) since the onset of the COVID-19 pandemic.
2. LGB persons will have increased these ACP activities more than heterosexual persons.

We proposed to address these questions with quantitative data from a large, national survey of older Canadians.

### **Method**

This study is based on an online survey focused on current experiences and future plans during the COVID-19 pandemic. The survey opened to an invitation page that screened respondents to those aged 55 or older and living in Canada. We chose 55 so as to increase the opportunity to examine the impact of COVID on those who might be employed and in what has been called the ‘Sandwich Generation’,<sup>26</sup> that is, those ‘sandwiched’ between generations of care recipients. The invitation briefly described the purpose of the survey as to explore ‘any pandemic-related stressors you may be experiencing, issues you are facing regarding healthcare, and any actions taken toward planning for future care’. We further indicated that we were seeking both those who have and have not contracted COVID-19 and that we were seeking respondents from the general population as well as targeting responses from minority groups, including those who self-identify as LGBT.

From this invitation, potential respondents could click on the consent page. Upon consent, respondents were able to enter the online survey, created using an online survey tool (www.surveymonkey.com). The study was approved by Simon Fraser University’s Research Ethics Review Board (approval number: 2020s0273).

The 61-item survey included basic demographic information and a series of items that concerned health and functional status, pandemic-related

stressors and social impacts, healthcare access, and planning for the future. The survey opened on 10 August 2020 and closed on 10 October 2020. The mean time spent to complete the survey was 13 min and 21 sec.

Respondents were recruited using social media, direct email, and Facebook advertising, as well as a comprehensive email campaign requesting assistance with recruitment from organizations serving older adults in general and LGBT, South Asian, and Chinese older adults in particular (Canada’s two largest visible minorities). Over 80 regional and/or national organizations assisted in promoting the study.

### *Measures*

The analyses reported here used the following measures: age in years; education; sexual orientation [choosing from heterosexual, homosexual, that is, lesbian or gay, bisexual (all with definitions provided), or a don’t know/no answer option]; gender identity (choosing from man, woman, nonbinary, or another gender category of their wording); transgender identity (responding yes or no); relationship status; employment status; living alone or with others; the size/nature of the community in which they live (rural area, less than 1000 people; small population center, between 1000 and 29,999 people; medium size population, between 30,000 and 99,999 people; and large urban population, >100,000 people); and planning for the future.

The ‘Planning for the Future’ section began with a definition of ACP, drawing from Sudore and colleagues:<sup>2</sup>

a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive care that is consistent with their values, goals, and preferences during serious and chronic illness.

It was also noted that ACP may include the preparation of documents, and respondents were asked which, if any, of the following documents they had prepared prior to the COVID-19 outbreak (in one question) and since the outbreak (in another question). The response options included (with definitions) the following: Will; Power of Attorney for Property; Continuing/Enduring Power of Attorney; Advance Directive; Power of

Attorney for Medical Care; or No Change/Preparation of Documents.

Finally, two questions were posed related to conversations in which respondents may have engaged about ACP. Specific examples were offered, such as 'I'd like to receive intensive care for an illness or injury, as long as my brain is not damaged'. Respondents were provided a range of options from which they could select all that apply, including no (no discussion); or yes, with a spouse/partner; a family member; a friend; a doctor; or other including a space for respondents to enter a response of their wording. As above, these questions were framed, in the first instance, as prior to the COVID-19 outbreak and, in the second instance, since the COVID-19 outbreak. The survey, and final report of the study, may be found at <http://www.sfu.ca/lgbteol.html>

### *Analyses strategy*

We used chi-square analyses to compare the frequency of ACP documents prepared or revised and the frequency of care discussions undertaken by both sexual orientation and gender, as well as sexual orientation within gender. We examined the likelihood of taking ACP actions and engaging in care discussions both prior to and since the pandemic outbreak using binary logistic regression. We created dichotomous categories of actions taken (i.e. having prepared one or more of the series of documents or preparation of none of the documents), both prior to and since the outbreak of the COVID-19 pandemic. We created a comparable variable for care discussions, that is, having had a discussion of care decisions and choices (with at least one person or with no one) both prior to and since the onset of the pandemic. As above, and with the additional risk of overfitting the logistic regression model which would compromise the overall results,<sup>27</sup> we combined the bisexual sample with the gay and lesbian sample for these analyses and compared heterosexual with LGB older adults. In addition, given that both document preparation and discussions varied by gender, as well as with age and education level, these variables were also entered in the regression equations.

## **Results**

### *Sample*

In total, 4974 respondents entered our survey, with 1660 entering through web link (i.e. through

organizational referrals and email links: 33% of the sample) and 3314 (67% of the sample) from social media ads, primarily Facebook. Of the total, 484 gave consent but did not complete any questions; 110 left the survey either before answering or before finishing the demographic questions (i.e. the first 15 questions) and were excluded. A further 360 respondents left the survey before completing the 'Advance Care Planning' section (the final questions on the survey). Finally, our analytic sample also excludes 89 respondents who indicated 'don't know' or 'no answer' to the sexual orientation question, 19 respondents who identified as nonbinary, and 16 who indicated an additional gender category (totaling a loss of 97 additional respondents, given overlap in categories). Transgender persons who identified as either men (3 of 22 respondents) or women (12) were included, respectively, in those gender categories. These eliminations were due to the small and sometimes empty cells that emerged when these latter gender identity and the 'don't know/no answer' sexual orientation categories are dispersed across the dependent measures in preliminary analyses. In addition, in the analyses reported below, bisexual women were grouped with lesbian women and bisexual men were grouped with gay men, given the otherwise small cell sizes (and some empty cells).

Thus, the analytic sample (upon which the following analyses are computed) comprised 3923 Canadians between the ages of 55 and 99 years (mean age of 67.0), 3628 of whom identified as heterosexual, 233 as gay or lesbian, and 62 as bisexual. The vast majority of respondents identified as women (3033; 77% of the sample) and 890 identified as men. Reflective of the general population of older adults in Canada, a majority identified as White (88%). There were some age differences (those in the heterosexual group were older, on average), relationship status differences (LGB respondents were more likely to be single), and differences in living arrangement (LGB respondents were more likely to live alone) and community size (LGB respondents were more likely to live in larger urban centers). See Table 1 for a description of the sample demographics, including all statistical comparisons.

### *ACP documents and discussions*

We compared sexual orientation and gender groups, as well as sexual orientation within gender, on the percentage of respondents who had

**Table 1.** Sociodemographic characteristics by gender and sexual orientation.

N	Gender		Sexual orientation					Total 3923					
	Women	Men	Heterosexual women	Lesbian	Bisexual women	Women Total	Heterosexual men		Gay men	Bisexual men	Men Total		
			2882	106	45	3033	746	127	17	890	3628	233	62
Age (mean)	66.7	65.3	64.8	66.7	68.7	68.2	67.0	67.1 <sup>a</sup>	65.7	64.9			
Relationship status (%)													
Single	7.3	20.8**	22.2**	7.9	6.2	8.5	8.1	7.0	21.9**	17.7**			
Married	59.4**	49.1**	24.4	58.6	74.8**	71.2**	61.4	62.6**	51.9**	29.0			
Widowed	14.4	10.4	15.6	14.3**	5.1	5.7	12.4	12.5	9.4	14.5			
Divorced/Separated	18.9	19.8	37.8**	19.2**	13.9	14.5	18.1	17.9	16.7	38.7**			
Living arrangement (%)													
Alone	31.3	40.6**	51.1**	31.9**	21.4	23.5	30.0	29.3	36.5**	48.4**			
Community (%)													
Rural	13.6*	8.5	2.2	13.3	14.3	13.4	13.3	13.8**	7.7	6.5			
Small population	22.7	17.0	17.8	22.4	21.4**	19.7	21.8	22.4**	13.3	16.1			
Medium population	17.0	17.0	8.9	16.9	15.1	14.5	16.4	16.6	13.3	11.3			
Large urban population	46.7	57.5**	71.1**	47.4	49.1	52.5**	48.6	47.2	65.7**	66.1**			
Education (%) <sup>a</sup>													
High school or less	20.4*	12.3	8.9	19.9	18.2	18.1	19.5	19.9*	15.5	9.7			
Certificate	34.2	23.6	35.6	33.8	33.2	31.5	33.3	34.0**	21.0	38.7**			
Bachelor's degree	22.1	30.2	20.0	22.3	19.4	20.2	21.8	21.5	27.9	17.7			
Graduate degree	18.9	34.0**	35.6**	19.7	23.9	25.1**	20.9	20.0	33.0**	32.3			
Employment status (%)													
Employed	21.0	25.5	28.9	21.3	20.0	20.7	21.2	20.8	24.0	30.6*			
Retired	64.7**	52.8	42.2	64.0	65.8	64.7	64.1	64.9**	57.5**	41.9			
Not working	14.3	21.7**	28.9**	14.7	14.2	14.6	14.7	14.3	18.5	27.4**			

<sup>a</sup>Excluding 'other' write-in category (4.5%).  
<sup>\*</sup>F, *p* < 0.001; <sup>\*</sup>χ<sup>2</sup>, *p* < 0.05; <sup>\*\*</sup>χ<sup>2</sup>, *p* < 0.005.

**Table 2.** Gender identity, sexual orientation, and advance care planning documents and discussions *prior to* pandemic onset.

N	Gender						Overall total 3923	Sexual orientation	
	Women			Men				Heterosexual 3628	LGB 295
	Heterosexual 2882	Lesbian and bisexual 151	Total 3033	Heterosexual 746	Gay and bisexual 144	Total 890			
Will (%)	67.9	65.6	67.8	56.3	64.6	57.6	65.5	65.5	65.1
POA-property (%)	44.6	42.4	44.5	35.5	39.6	36.2	42.6	42.8	41.0
POA-enduring (%)	28.4	27.8	28.4	23.9	30.6	24.9	27.6	27.5	29.2
Advance directive (%)	19.8	25.2	20.1	14.3	26.4**	16.3	19.2	18.7	25.8**
Representation agreement (%)	36.3	42.4	36.6	28.3	34.7	29.3	34.9	34.6	38.6
Care discussion (%)	64.3	76.8**	65.0	50.0	59.7*	51.6	61.9	61.4	68.5*

LGB, lesbian, gay, and bisexual; POA, power of attorney.  
\* $\chi^2$ ,  $p < 0.05$ ; \*\* $\chi^2$ ,  $p < 0.01$ .

prepared specific ACP documents and held discussions *prior* to the outbreak of the COVID-19 pandemic. Results may be seen in Table 2. Two significant sexual orientation group differences were noted: LGB respondents were more likely to have completed an advance directive [ $\chi^2(1) = 8.795$ ,  $p < 0.01$ ] and to have had care discussions [ $\chi^2(1) = 5.817$ ,  $p < 0.05$ ] than were heterosexual women and men. Comparing sexual orientation groups within gender, gay and bisexual men were more likely to have completed an advance directive [ $\chi^2(1) = 12.842$ ,  $p < 0.01$ ] and to have engaged in a care discussion [ $\chi^2(1) = 4.568$ ,  $p < 0.05$ ] than were heterosexual men. The only significant difference for women was found in analyses of care discussions, engaged in by lesbian and bisexual women [ $\chi^2(1) = 9.834$ ,  $p < 0.01$ ] more frequently than by heterosexual women.

Similar comparisons were made on the percentage who had completed or modified specific ACP documents and discussions *since* the outbreak of the COVID-19 pandemic. Results may be seen in Table 3. Although the overall numbers are substantially smaller, a broader array of differences was uncovered. Significant differences were noted

on all documents: Will [ $\chi^2(1) = 3.757$ ,  $p = 0.05$ ], POA-Property [ $\chi^2(1) = 4.413$ ,  $p < 0.05$ ], POA-Enduring [ $\chi^2(1) = 9.902$ ,  $p < 0.005$ ], Advance Directive [ $\chi^2(1) = 4.558$ ,  $p < 0.05$ ], Representation Agreement [ $\chi^2(1) = 6.403$ ,  $p < 0.05$ ], and Care Discussions [ $\chi^2(1) = 5.817$ ,  $p < 0.05$ ]. In all cases, LGB respondents prepared/modified these documents and engaged in care discussions, in greater proportion, than heterosexual respondents since the onset of the pandemic. Furthermore, in each of these cases, gay and bisexual men completed/modified the documents more frequently than did heterosexual men, with no significant differences noted for women: Will [ $\chi^2(1) = 12.403$ ,  $p < 0.005$ ], POA-Property [ $\chi^2(1) = 10.762$ ,  $p < .005$ ], POA-Enduring [ $\chi^2(1) = 15.495$ ,  $p < 0.005$ ], Advance Directive [ $\chi^2(1) = 8.740$ ,  $p < 0.05$ ], and Representation Agreement [ $\chi^2(1) = 7.617$ ,  $p < 0.05$ ]. Both gay and bisexual men as well as lesbian and bisexual women engaged in care discussions more frequently than heterosexual men [ $\chi^2(1) = 4.568$ ,  $p < 0.05$ ] and heterosexual women [ $\chi^2(1) = 9.834$ ,  $p < .05$ ], respectively.

Two questions were posed inquiring with whom such discussions had taken place, both prior and

**Table 3.** Gender identity, sexual orientation, and advance care planning documents and discussions *since* pandemic onset.

N	Gender						Overall total 3923	Sexual orientation	
	Women			Men				Heterosexual 3628	LGB 295
	Heterosexual 2882	Lesbian and bisexual 151	Total 3033	Heterosexual 746	Gay and bisexual 144	Total 890			
Will (%)	5.9	6.0	5.9	3.6	10.4**	4.7	5.6	5.5	8.1*
POA-property (%)	2.8	2.6	2.8	2.0	6.9**	2.8	2.8	2.6	4.7*
POA-enduring (%)	1.9	2.6	1.9	1.2	6.3**	2.0	2.0	1.8	4.4**
Advance directive (%)	2.2	3.3	2.2	0.9	4.2*	1.5	2.0	1.9	3.7*
Representation agreement (%)	2.5	4.0	2.6	1.7	5.6*	2.4	2.5	2.3	4.7*
Care discussion (%)	44.0	57.6*	44.6	34.6	40.3*	35.5	42.6	42.0	49.2*

LGB, lesbian, gay, or bisexual; POA, power of attorney.  
\* $\chi^2$ ,  $p < 0.05$ ; \*\* $\chi^2$ ,  $p < 0.005$ .

subsequent to the onset of the pandemic. For these analyses, only those who reported to be married or living as married were included in the analysis of spouse or partner as discussant (since this was an option only available to them); all respondents are included in the remaining analyses. For those who were partnered, a significant difference was noted by sexual orientation: LGB respondents were more likely to have had discussions prior to the pandemic outbreak with their spouses/partners than were heterosexual respondents, with respective percentages of 74.1 and 56.8 [ $\chi^2(1) = 16.067$ ,  $p < 0.001$ ]. The same pattern applied across gender, that is, gay and bisexual men and lesbian and bisexual women were more likely to have had discussions with their spouses and partners than were heterosexual men and women, respectively. No significant differences were noted on discussions with family; 34.7% of respondents reported that they had had care discussions with a family member. Significant differences were noted on discussions with friends [ $\chi^2(1) = 34.936$ ,  $p < 0.001$ ]: 22.4% of LGB respondents had had care discussions with friends compared with 10.9% of heterosexual respondents (consistent across gender). A similar difference was found with discussions with a doctor, although the

percentages are very low [ $\chi^2(1) = 4.250$ ,  $p < .05$ ]: 6.8% of LGB respondents had had care discussions with their doctor compared with 4.2% of heterosexual respondents.

A comparable question was posted about with whom such discussions have taken place since the outbreak of the pandemic. For those who were partnered, a significant difference was noted by sexual orientation: LGB respondents were more likely to have had discussions with their spouses/partners since the pandemic outbreak than were heterosexual respondents, with respective percentages of 50.4 and 39.5 [ $\chi^2(1) = 6.487$ ,  $p < .01$ ]. Only for women did the same pattern apply, that is, comparing lesbian and bisexual women with heterosexual women with no differences among men. No significant differences were noted with discussions with either family (averaging 21.9% across groups) or with a doctor (averaging 2.0% across groups). Significant differences were noted with discussions with friends with whom, as above, LGB persons were more likely to have had care discussions: 20.0% of LGB and 8.7% of heterosexual respondents, respectively [ $\chi^2(1) = 40.223$ ,  $p < 0.001$ ], consistent across gender.



**Table 4.** Logistic regression models predicting ACP actions.

Variable	B	SE	Wald $\chi^2$	p	OR (95% CI)
ACP actions taken prior to the pandemic (none or one+ documents)					
Constant	-5.560	0.387	206.935	0.001	
Age (years)	0.071	0.005	172.647	0.001	1.074 (1.063–1.085)
Education (levels)	0.435	0.037	140.686	0.001	1.545 (1.438–1.660)
Gender identity (women compared with men)	0.661	0.088	56.383	0.001	1.938 (1.630–2.303)
Sexual orientation (LGB compared with heterosexual)	0.113	0.141	0.634	0.426	1.119 (0.848–1.477)
ACP actions taken since pandemic onset (none or one+ documents)					
Constant	-3.552	0.640	30.854	0.001	
Age (years)	0.001	0.009	0.015	0.903	1.001 (0.984–1.019)
Education (levels)	0.201	0.063	10.125	0.001	1.222 (1.080–1.383)
Gender identity (women compared with men)	0.369	0.172	4.578	0.032	1.446 (1.031–2.027)
Sexual orientation (LGB compared with heterosexual)	0.466	0.217	4.619	0.032	1.594 (1.042–2.439)

ACP, advance care planning; CI, confidence interval; LGB, lesbian, gay, and bisexual; OR, odds ratio; SE, standard error.

### Binary logistic regressions

Turning first to pre-pandemic ACP document preparation, the logistic regression model was statistically significant,  $\chi^2(4) = 387.95$ ,  $p < 0.001$ . Significant effects were found for age [odds ratio (OR) = 1.074], education (OR = 1.545), and gender identity (women compared with men, OR = 1.938). Sexual orientation was not a significant predictor. The logistic regression model considering ACP document preparation since the onset of the pandemic was also statistically significant,  $\chi^2(4) = 20.664$ ,  $p < 0.001$ . Significant effects were found for education (OR = 1.222) and gender identity (women compared with men, OR = 1.446) as well as for sexual orientation (LGB compared with heterosexual, OR = 1.594), as reported in Table 4.

The logistic regression model for pre-pandemic care discussions was statistically significant,  $\chi^2(4) = 115.998$ ,  $p < 0.001$ . All variables entered in the equation were significant ( $p < 0.001$ ), as reported in Table 5: age (OR = 1.026), education

(OR = 1.192), gender identity (women compared with men, OR = 2.027), and sexual orientation (LGB compared with heterosexual, OR = 1.688).

The logistic regression model considering care discussions since the onset of the pandemic was also statistically significant,  $\chi^2(4) = 35.750$ ,  $p < .001$ . Only gender (women compared with men, OR = 1.613) and sexual orientation (LGB compared with heterosexual, OR = 1.512) were significant predictors of having had care discussions.

### Discussion

Revealed in the above analyses are the influences of sexual orientation on ACP as filtered through the exigencies of the COVID-19 pandemic. Our hypothesis that LGB persons would be more likely than heterosexual persons to have prepared ACP documents and to have engaged in care discussions since the pandemic onset was supported; our hypothesis that the pandemic would increase such behaviors across all persons was only

**Table 5.** Logistic regression models predicting care discussions.

Variable	B	SE	Wald $\chi^2$	p	OR (95% CI)
Care discussions prior to the pandemic (none or with one+ persons)					
Constant	-2.272	0.337	45.436	0.001	
Age (years)	0.022	0.005	30.564	0.001	1.026 (1.017-1.036)
Education (levels)	0.176	0.033	28.022	0.001	1.192 (1.117-1.272)
Gender identity (women compared with men)	0.707	0.082	73.544	0.001	2.027 (1.725-2.383)
Sexual orientation (LGB compared with heterosexual)	0.524	0.138	14.432	0.001	1.688 (1.289-2.212)
Care discussions since pandemic onset (none or with one+ persons)					
Constant	-1.356	0.323	17.646	0.000	
Age (years)	0.008	0.005	3.094	0.079	1.008 (0.999-1.017)
Education (levels)	0.046	0.032	2.096	0.148	1.047 (0.984-1.115)
Gender identity (women compared with men)	0.478	0.084	32.801	0.001	1.613 (1.370-1.900)
Sexual orientation (LGB compared with heterosexual)	0.413	0.127	10.629	0.001	1.512 (1.179-1.938)

CI, confidence interval; LGB, lesbian, gay, or bisexual; OR, odds ratio; SE, standard error.

partially supported. The chi-square analyses addressing ACP efforts since the pandemic onset revealed a greater proportion of LGB persons having taken some action (preparing or revising) on all of the documents. The regression analysis demonstrated that LGB persons were more likely to engage in at least some ACP since the onset of the pandemic; in these analyses, women too were more likely to engage in some ACP both prior to and since the onset of the COVID-19 pandemic, consistent with previous research.<sup>6</sup>

One potential explanation, applicable to the experiences of both LGB persons and the results for women, may be found in the research on prosocial behaviors. As much as ACP is a guide to one's own future care, so too is it an expression of consideration for another person who may be overseeing such care; in such manner, ACP may be seen as a prosocial act, providing for another person the knowledge they need to make decisions often under great stress. Prosociality among women has been linked to gender roles and noted

particularly in relational contexts.<sup>28,29</sup> ACP efforts and engagement may be seen as acts of care. Prosociality among LGBT persons may be similarly understood but also has been linked to social inclusion and identity affirmation,<sup>30</sup> often in the face of stigma and discrimination.<sup>31,32</sup> As such, the engagement in ACP may be seen as respondents acting to protect themselves and group interests:<sup>32</sup> their future care and the thwarting of potential interference of others with such decisions.

Given that few significant sexual orientation differences were found in ACP behaviors prior to the pandemic, we propose that perhaps a stronger (but related) reason for these actions on the part of LGB persons lies in their previous experience of an epidemic: HIV/AIDS. HIV is not the only previous epidemic likely experienced by our respondents [e.g. severe acute respiratory syndrome (SARS), H1N1, polio]; however, it is an epidemic disproportionately affecting the LGBT community. The caring for so many partners and

friends, especially by LGBT persons, and the plethora of deaths attended and witnessed at a time when so many others, including the government, turned away certainly have an impact. This impact, this stressful memory and legacy, may be heightened in the press of this new pandemic, encouraging efforts to protect and prepare. Such findings are broadly consistent with the previously described study by de Vries and colleagues<sup>20</sup> showing that in association with government exclusion (i.e. denial of marriage rights), LGBT persons were more likely to complete ACP documents. de Vries and colleagues<sup>20</sup> invoked notions of forced self-reliance and minority stress<sup>33</sup> to account for such findings. Such findings and interpretations are also aligned with colloquial accounts, news reports,<sup>34</sup> and pilot research wherein gay men commented on how COVID-19 is ‘the second pandemic of our lives’ and on how the LGBT community is handling the pandemic likening it ‘to what the AIDS epidemic felt like’ (p. 31).<sup>35</sup> This ‘been here before’ attitude,<sup>36</sup> and the action it engenders, may be a driving factor for the increased ACP efforts, across all documents, of the respondents of our sample, and perhaps especially gay men who bore much of the brunt, particularly in the early years of the HIV/AIDS crisis.

A key feature of ACP is the communication of one’s beliefs, values, and wishes for care during a serious health condition and at end of life. Interestingly, almost 62% of respondents had engaged in care discussions prior to the pandemic, consistent with other Canadian research,<sup>6</sup> and almost 43% had engaged in such discussions since the pandemic onset. It is not possible to tell whether the pandemic was the source of such recent discussions, although such a motivator seems likely, and reasonable. Talking about the location and sort of care that would be desired in the case of a health crisis seems like a thoughtful response to a global health threat.

LGB respondents were more likely to have had discussions about the care they wish to receive should the need arise prior and subsequent to the onset of the pandemic, similar to the results on ACP actions taken and consistent with the sexual minority interpretation offered above. Women were over twice as likely as men to have had discussions prior to the pandemic and over one and one-half times more likely since the pandemic onset, comparable to ORs for gay and bisexual men and lesbians and bisexual women. For those

with spouses or partners, over two-thirds of gay and bisexual men and over three-quarters of lesbian and bisexual women had had discussions, compared with just over half of heterosexual men and women. There are likely many reasons for couples not having had such discussions, including issues of culture, the North American avoidance of death,<sup>10</sup> and dynamics within a relationship; these percentages in this relationship, however, set the upper limit of discussion likelihood with anyone of our sample, and probably more generally given the intimacy of marital and partnership relationships.

Family members were those with whom discussions were next most likely to have taken place, both prior to and since the onset of the pandemic. Neither sexual orientation nor gender differences were noted in these percentages. The prominent place of these discussants is consistent with the hierarchical compensatory framework of potential caregivers<sup>37</sup> and public policy. In British Columbia, for example, the government has provided a list of temporary substitute decision-makers (TSDM) from which the healthcare provider must choose if an individual is incapable of doing so, does not have a legally appointed decision-maker, and does not have an advance directive.<sup>38</sup> A choice must be made from the following list of the first person who is willing, available, and qualified: spouse, adult child, parent, sibling, grandparent, grandchild, anyone related by birth or adoption, a close friend, and a person immediately related to the individual by marriage; in the absence of such persons, a public guardian or trustee is appointed.<sup>39</sup>

Given the often-conflicted biological kinship ties and the concomitant salience of logical kinship connections (to borrow a term from Armistead Maupin<sup>40</sup>) for older LGBT persons, the role of friends is significant in the lives of older LGBT persons.<sup>41</sup> This finding was borne out again in these data with the significantly higher likelihood of having had care discussions with friends, both prior to and since the pandemic onset among LGB persons, relative to heterosexuals. That the category of ‘friends’ appears so low on the list of accepted possible TSDMs in British Columbia and is absent in other provincial lists (e.g. Ontario) is a source of serious concern to LGBT persons.

Finally, discussions with a doctor were rare among the respondents of this sample, both prior to and since the onset of the COVID-19

pandemic. These findings too are consistent with previous research. Teixeira and colleagues,<sup>6</sup> for example, found that about 10% of their national sample of Canadian adults had had a discussion with a healthcare provider regarding healthcare treatment preferences in the event that they were unable to speak for themselves. The question in our survey of older adults was focused more particularly on a doctor, limiting the comparability. Still, the overall percentage of doctor discussions prior to the COVID outbreak is similarly low (4.2% for heterosexuals), though modestly (significantly) higher among LGB persons (6.8%), perhaps owing to the reasons described above (i.e. protection, planning, and perhaps confrontation in the face of stigma). Since the pandemic onset, there were no sexual orientation (or gender) differences among the 2.0% of respondents who have had such a discussion. Teixeira and colleagues<sup>6</sup> note that such low percentages implicate not only the adults in their research but also physicians who they report as reluctant to initiate a conversation for personal, legal, and perhaps cultural reasons.

### *Implications*

There are many and varied implications from this research. Drawing from the results addressed directly above, for example, these implications include finding ways to support conversations about future care and treatment preferences with physicians. These efforts could focus on both the patient and physician in these relationships and perhaps the use of tools to facilitate such discussions: the current work of the pan-Canadian ACP team, as referenced above. Efforts could also focus on facilitating and supporting discussions between spouses/partners, with families and with friends; illustrative guides, sample texts, and other supports could assist in navigating these potentially stressful, but needed and intimate, conversations. Getting information to those who seek it remains a challenge; we have attempted to address this in our previous research (particularly for LGBT older adults; see Beringer and colleagues<sup>42</sup>), but our efforts are similarly Internet-dependent and consequently limited.

More broadly representative of these results, however, are the issues sexual orientation and gender. Focusing on both issues suggests contexts (interpersonal and political) into which efforts could be tapped to promote ACP. There is clearly

a need for more tailored efforts<sup>43</sup> perhaps drawing on the strengths evidenced by the groups identified. If interpretations are correct, promotional efforts with women could elaborate on the care (and caregiving) and interpersonal concerns; for LGB persons, promotional efforts would require a more inclusive approach (e.g. of non-traditional caregivers) and more inclusive language. A strength-based approach could also build on the historical responses to HIV/AIDS by LGBT persons, invoking notions of resilience, competence, and care.

That almost 55% of the respondents have had care discussions and just over 60% have prepared wills offers a base from which to build these promotional efforts. These are impressive numbers, even as there is certainly room for growth (i.e. only about 19% of respondents had completed an advance directive). There is a platform from which to reach these persons offered by the COVID-19 pandemic. Many respondents (and especially LGB persons) are finding and using that platform themselves as evidenced in the percentage of document initiation or modification and discussion engagement since the pandemic onset, but there are opportunities for expansion and to help frame a person and care-focused response to the current crisis. Age and education are similarly implicated, as seen in the regression analyses and previous research,<sup>6</sup> and offer touch points for the further consideration of ACP.

### *Limitations and conclusion*

Notwithstanding the size and complexity of the sample, it was not randomly generated and may not be representative of the Canadian population. The fact that the survey was conducted exclusively in English certainly limits the representativeness, as do the community-dwelling, computer and Internet access, and literacy parameters of the sample. Although definitions for advance care terms were provided, terminology differs between provinces and cultures and ambiguity around these terms may have an effect on comprehension. Similarly, the questioning of sexual orientation and gender identity remains a challenge and is evolving, and our probes may not have included all.

Nonetheless, this is among the first, large studies, inclusive of sexual orientation, to examine ACP among older Canadians in the time of COVID-19. It offers a glimpse into the ACP preparations of older Canadians (highlighting the need for

more and focused educational efforts to increase uptake), the role of gender, and the important role of sexual orientation (suggesting the sequelae of the HIV/AIDS pandemic). We believe this study is a significant contribution to the literature on responses to the COVID-19 pandemic and ACP. Context matters.

### Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study is part of a larger project (iCAN-ACP) funded by a grant from the Canadian Frailty Network (formerly Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) program.

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