

A Population-Based Study on Advance Directive Completion and Completion Intention among Citizens of the Western Canadian Province of Alberta

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Abstract / Determining what proportion of the public has completed an advance directive and which population subgroups complete or do not complete such a directive is crucially important for planning purposes. Our research objective was to examine and compare advance directive completion, intention to complete, and noncompletion rates among citizens of one Canadian province. A telephone survey was conducted with 1,203 Albertans who met gender, age, and other requirements for a representative sample. When asked, "Do you have a living will or personal directive?" 43.6 percent reported having completed a directive and 42.1 percent indicated that they planned or intended to complete one. Completion rates increased with age. Widowed, self-employed, and retired people, and those who had lost a family member or friend and had other select end-of-life experiences and viewpoints were significantly more likely to have completed one. Although older people more often had an advance directive, personal life-and-death experiences should be recognized as major influences on directive completion.

Résumé / Pour les besoins de planification, il est très important de pouvoir déterminer quelle proportion de la population a fait son testament de fin de vie et quelle proportion des sous-groupes de cette même population est en train de le faire ou bien ne l'a pas encore fait. L'objectif de notre recherche était de déterminer à quel stade en était la population d'une province du Canada, au sujet du testament de vie soit: a) il a été fait; b) il est sous planification; c) aucun n'est prévu. Nous avons fait en Alberta un sondage téléphonique auprès de 1203 personnes sélectionnées selon l'âge, le genre et d'autres exigences pré-déterminées par les chercheurs pour obtenir un échantillon représentatif de la population. A la question: «Avez-vous fait un testament de fin de vie ou avez-vous donné des directives

anticipées de fin de vie?» — 43,6 pourcent ont répondu l'avoir fait, et 42,1 pourcent ont indiqué qu'ils en avaient l'intention ou que c'était déjà planifié. Plus les répondants étaient âgés plus ils étaient nombreux à avoir rempli les documents nécessaires. Les veufs/veuves, les travailleurs et travailleuses autonomes, les personnes retraitées, ceux/celles qui avaient perdu un membre de la famille ou un être cher ou encore qui avaient vécu de difficiles expériences de fin de vie ou qui avaient des points de vue différents sur le sujet étaient plus nombreux à avoir fait connaître leurs volontés. Il est cependant important de souligner que certaines expériences personnelles difficiles, liées à des questions de «vie et de mort», influencent souvent les personnes et les motivent à signifier leurs directives anticipées de fin de vie à leurs proches.

INTRODUCTION

The advance directive movement was initiated in the United States in the 1960s. Similar legislation has since been passed in many other countries to permit and encourage the development and use of advance directives (1, 2). Advance directives typically document personal healthcare preferences for later use in the event that a person loses his or her ability to make or communicate healthcare preferences (3). Such a document will often specify that life support should not be started or continued if the person who prepared and signed the document is mortally ill. Considerable variability in legislated practice exists, as laws differ from one country to another and across states or provinces in the same country. In Alberta, a western Canadian province, the *Personal Directives Act* came into effect in 1997; it stipulates that one or more persons can be identified as proxy deci-

sion makers and others can be identified as individuals who should not be considered for that role (3). The Act was amended in 2008 to create a registry where people can house and thus safeguard their directives (3). Legal assistance with directive development or completion is not required in Alberta. A valid directive can be written by any competent adult and simply dated, signed, and witnessed; it can also be revised or rescinded at any time by its author (3). Adult Albertans (aged 18 and over) can thus not only create but also register their advance directives at no cost.

Advance directives are broadly intended to enhance autonomous decision making and safeguard the right of competent adults to direct their own healthcare. Despite concern, in the early years, about their lack of impact (4, 5), advance directives have been found influential in healthcare decision making in recent years in Canada, the United States, and other countries (1, 2). However, low completion rates have been a problem for some time now. The most current Canadian completion rate, reported in an online publication, was 10 percent (1). This indicates that most Canadians are unprepared for a serious illness and the resultant loss of ability to engage in autonomous decision making (6). With population aging accelerating in Canada and elsewhere (7), and with higher rates of chronic or incurable illness now evident globally, advance directives are expected to grow in significance. An evidence-based understanding of the current rate of directive completion is needed for healthcare policy and planning. Determining which population subgroups are completing advance directives and which are not is crucially important for public education efforts and for warning healthcare professionals which patients are at risk of receiving unwelcome treatments when they are ill and unable to speak for themselves.

BACKGROUND

To inform this study, a search for research articles published between 1960 and 2011 in journals indexed in Medline was undertaken using the search terms "advance directive," "personal directive," "(enduring/durable) power of attorney," and "living will"; these were cross-referenced with "healthcare/health care." Over 5,000 articles were found. Their publication dates reveal an ongoing interest after 1976, when the Karen Ann Quinlan case made the need for advance directives apparent (8).

After narrowing the results to public surveys or polls through a keyword search and a manual search of titles and abstracts, we were able to identify only two papers, both American, that reported

a general public survey. The first was a secondary analysis of data obtained through a random-sample telephone survey conducted in 1998 and 1999 in Hawaii, which found that 29 percent of Hawaiians had a living will or an advance directive (9). A more recent telephone survey undertaken by Pollack, Morhaim, and Williams involved a representative cross-section of adults in Maryland (10). Of the 1,195 surveyed, 34 percent reported having an advance directive.

Other investigations identified in this search involved population subgroups; completion rates varied considerably across and among them. For instance, the completion rate identified for hospital emergency department patients ranged from 7.9 percent (11) to 27 percent (12). Taylor and colleagues' Australian study of a random sample of these patients is noteworthy: although only 7.9 percent of the 403 patients they sampled indicated that they had completed a directive, 68.5 percent said that they might do so (11). Another finding of the reviewed studies is what appears to be a rate increase over time. For instance, a 1999 American study involving 5,117 older Health Maintenance Organization (HMO) members found that one-third had an advance directive on file (13). Another study — this one of residents at six Connecticut nursing homes — similarly revealed that 34.7 percent had an advance directive; the 1990 *Patient Self-Determination Act* was credited with raising this rate from 4.7 percent (14). A slightly higher rate of 38 percent was found around this time in a representative sample of 2,864 Americans infected with HIV (15). More recently, a 2002 telephone survey of a random sample of Oklahoma residents 60 years and older revealed that just over half had a living will, two-fifths had a durable power of attorney for healthcare, and one-third had both (16). A 2004 countrywide survey of American nursing home residents showed that 69.9 percent had at least one written directive, ranging from an organizational care plan (approved by the resident or a family member) to legal documents such as an enduring power of attorney for financial and/or surrogacy purposes (17).

As these studies involved different subject groups and were undertaken over many years in a number of countries, it is not surprising that completion rates vary. Neither is it surprising that there was a range of sociodemographic and other factors associated with higher or lower completion rates. For instance, a 1992 American study found that marital status was not a factor bearing on directive completion; instead race/ethnicity was identified as important, with White respondents more likely to have an advance directive

than non-Whites (18). A subsequent American study showed that race/ethnicity, marital status, sex, and self-rated health were not factors for advance directive completion (11). Three studies found higher rates among people with a greater level of education (16, 18, 19). One study reported that advance directive completion rates increased as the practice of withholding or withdrawing life support became more commonplace (20). Most studies revealed higher rates among older persons (16), although health problems and lower self-reported health status were often cited as cofactors (9, 10, 12, 13, 21-23).

Pollack, Morhaim, and Williams's recent population-based survey of 1,195 Maryland adults is perhaps the most significant in terms of identifying current and potentially generalizable sociodemographic and other factors related to directive completion (10). This American study revealed that older persons (more often than younger ones), Whites (more often than Blacks), and persons with health problems or those with an unhealthy friend or family member (more often than those with no health problems) were more likely to have completed a directive. The study also identified three factors related to not completing a directive: lack of familiarity with advance directives, uncertainty about the process of creating one, and considering oneself too young or healthy to need one.

As such, the literature review revealed that few studies have been undertaken to determine general-public completion rates. Most studies to date have involved subpopulations, and their findings cannot be generalized to other subpopulations or to the same subpopulations in other countries. Another issue is that most studies were conducted over 10 years ago, which raises the concern that societal and healthcare developments in recent years may have had a considerable impact on completion rates. Although the testing of measures designed to increase advance directive completion rates is a recent research focus (24), it is important to map general-public completion rates, as, arguably, all adults should have an advance directive. It is also important to determine current sociodemographic and other factors linked to completion and noncompletion to enhance educational initiatives and other efforts to raise completion rates.

METHODS

A population-based survey was undertaken in mid-2010 to determine the completion rate and factors associated with completion or noncompletion among adult citizens of Alberta, a Canadian province. To obtain a representative sample, we

commissioned the Population Research Laboratory (PRL) at the University of Alberta to include questions on end-of-life plans, preferences, and experiences in its spring/summer telephone survey of Albertans. This survey focuses on healthcare topics, and it is one of many that the PRL carefully plans and conducts in order to achieve results that are representative (95 percent) of adults living in Alberta. The PRL population-based surveys are designed to obtain information from 1,200 adults who meet gender, age, and other provincial quota requirements.

We asked the PRL to gather this data because the organization has the infrastructure required to conduct telephone surveys and extensive experience in designing and conducting population-based telephone surveys and public opinion polls. In 2010, 3.7 million persons lived in Alberta; about 80 percent were aged 18 and over and 10 percent were 65 and over. For this survey, participation was voluntary. One respondent in each household who met the weighted criteria for inclusion was asked a series of sociodemographic and research questions. Those who answered the phone were screened for inclusion (the respondent had to be 18 or older and able and willing to answer English-language end-of-life questions). Each was informed about the study and told that he or she could decline to answer any or all questions. Of all those contacted, 21 percent agreed to participate. Some numbers were abandoned after 14 calls went unanswered; quota substitutions were made as required. The end-of-life questions included in this survey were devised by an international research team and pilot-tested by the PRL. Minor changes were made to improve the questions. The survey was conducted in May through July 2010, and data was provided to the research team later that year. Ethics approval was given in advance by a research ethics committee at the University of Alberta.

For the data analysis, we first looked at those who reported that they had completed a directive, intended or planned to complete one, or had no intention or plan to complete one. A total of 1,184 respondents answered the question on advance directives — a subset of the full representative sample of 1,203 adults who provided data for this study. Cross-tabulations with sociodemographic variables were then performed, followed by cross-tabulations with data obtained through the other questions on end-of-life experiences and viewpoints. These questions were designed to determine whether the respondent had experienced the death of a close family member or friend, had been involved in a decision to stop or not start life support, had cared for a dying person, and

believed that dying people should have the right to ask for and receive assistance to end their lives. These end-of-life questions were included because the team's previous research and literature reviews indicated that such factors could influence directive completion.

A logistic regression model was devised to predict the probability of completing a directive. This model expressed the dependent variable as a function of several independent variables, a form

of regression that is used when the dependent variable is dichotomous. Age group, education level, marital status, household size, and the responses to most research questions were identified as relevant independent variables for the model.

RESULTS

Table 1 highlights the sociodemographic characteristics of the surveyed population. As expected,

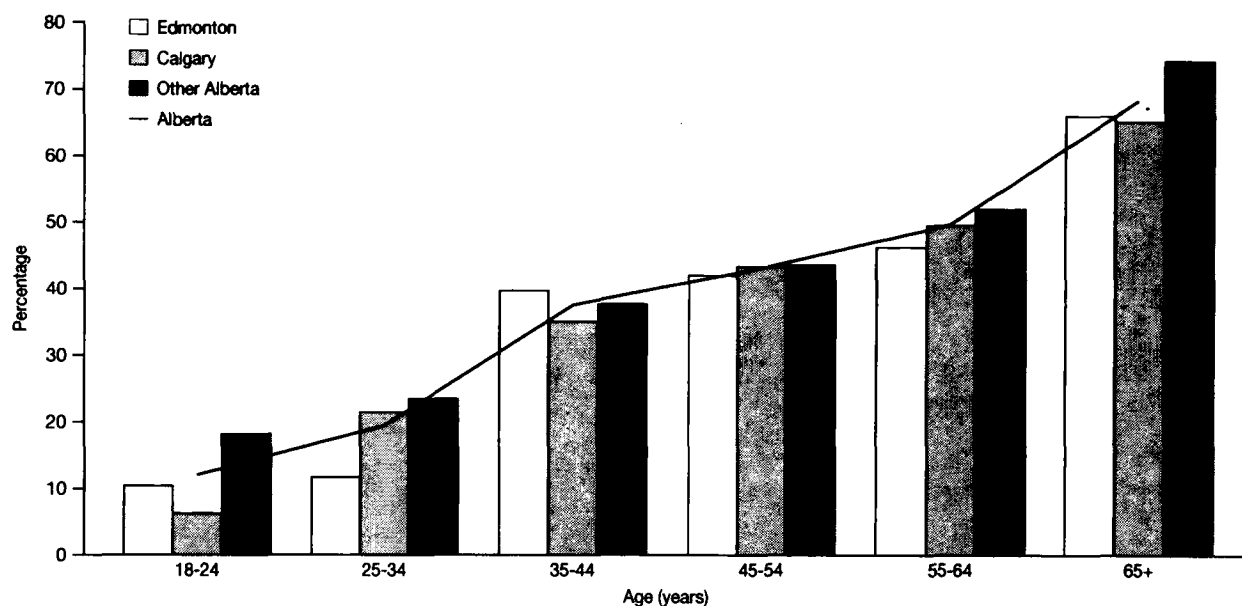
Table 1 / Sociodemographic Characteristics in Relation to Advance Directive Completion

	Total n* (%)	Directive completed %	Intend to complete %	No plan/ intention %	p-value**
Total	1,184	43.6	42.1	14.3	
Age (years)					<0.001
18-24	67 (5.8)	11.9	41.8	46.3	
25-34	145 (12.6)	19.3	56.6	24.1	
35-44	200 (17.4)	37.5	46.5	16.0	
45-54	263 (22.8)	43.0	44.9	12.2	
55-64	256 (22.2)	49.6	44.1	6.3	
65+	220 (19.1)	68.2	23.6	8.2	
Sex					0.033
Male	593 (50.1)	44.7	39.0	16.4	
Female	591 (49.9)	42.5	45.3	12.2	
Education					0.741
Less than high school	95 (8.1)	48.4	35.8	15.8	
High school completed	235 (19.9)	41.7	43.8	14.5	
Post-secondary	848 (72.0)	43.6	42.3	14.0	
Occupational Status					<0.001
Paid job	615 (52.2)	34.8	48.1	17.1	
Self-employed	189 (16.0)	54.0	35.4	10.6	
Paid job and self-employed	29 (2.5)	51.7	44.8	3.4	
Not working	345 (29.3)	52.8	35.1	12.2	
If Not Working***					<0.001
Retired	224 (76.7)	62.1	29.0	8.9	
Not Retired	68 (23.3)	33.8	49.5	17.6	
Marital Status					<0.001
Single	166 (14.1)	19.3	47.6	33.1	
Married	772 (65.4)	47.7	40.4	11.9	
Common-law	75 (6.4)	25.3	61.3	13.3	
Divorced	69 (5.8)	49.3	44.9	5.8	
Separated	27 (2.3)	51.9	37.0	11.1	
Widowed	72 (6.1)	66.7	27.8	5.6	
Residential Status					<0.001
Own home/condo	999 (84.9)	47.1	41.1	11.7	
Rental accommodation	178 (15.1)	24.2	48.3	27.5	
Location of Residence					0.522
Metro Edmonton	395 (33.4)	41.8	42.5	15.7	
Metro Calgary	393 (33.2)	43.3	41.5	15.3	
All Other	396 (33.4)	45.7	42.4	11.9	
Household Size					<0.001
One person	168 (14.2)	52.4	36.3	11.3	
Two persons	463 (39.2)	48.8	40.6	10.6	
Three persons	188 (15.9)	37.8	47.3	14.9	
Four or more	363 (30.7)	35.9	44.1	20.0	
Religious (self described)					0.032
Yes	467 (50.2)	46.7	39.8	13.5	
No	494 (49.8)	38.9	43.7	17.4	

* Numbers do not add up to the total survey sample of 1,203 respondents because of missing values.

** Pearson χ^2

*** Numbers do not add up to 345 because of missing values.

Figure 1 / Percentage of People with a Completed Personal Directive in Alberta, by Age and Region

given Alberta's population parameters, most (80.9 percent) were under the age of 65. The mean age was 50, and the range was from 18 to 96. Males and females were nearly equally represented; three-quarters were married or in common-law relationships. Each household had an average of 2.8 residents; 66.7 percent of households had no children. Most respondents (84.9 percent) lived in a house or condominium that they owned. In addition, nine-tenths reported that they had an education level of grade 12 or higher, and nearly three-quarters said that they were employed; their average annual personal income before taxes was in the \$40,000-to-\$45,000 range. Half (49.8 percent) reported no religious affiliation. The respondents were nearly equally divided between those who lived in or near the city of Edmonton, in or near the city of Calgary, and in all other places combined.

Among the 1,184 persons who responded to the advance directive question, 43.6 percent had completed a written personal directive, 42.1 percent planned or intended to complete one, and 14.3 percent did not want or intend to complete one. The distribution of responses in relation to sociodemographic variables cross-tabulated with directive completion, intention to complete, and noncompletion is shown in Table 1. As illustrated in Figure 1, completion rates increased with age. Only 11.9 percent of those aged 18 to 24 had a directive as compared to 68.2 percent of those aged 65 and over. Completion rates were similar across Edmonton, Calgary, and other regions (41.8 percent, 43.3 percent, and 45.7 percent, respectively). Rates were also similar for males and

females (44.7 percent and 42.5 percent, respectively).

As shown in Table 2, results of three of the tests performed on the information obtained through the questions on end-of-life viewpoints and experiences in relation to the options of having completed a directive, planning or intending to complete one, or not planning or intending to do so were found to be significant. The experience of having had a close family member or friend pass away was strongly related to directive completion, as over twice as many of those who had undergone this experience (44.8 percent) reported having completed a directive as compared to those who had not had this experience (20.3 percent). Notably, 32.2 percent of respondents who had not experienced the death of a close family member or friend reported no plan or intention to complete a directive. Significantly higher completion rates were also found among those who had cared for a dying person (50.7 percent) versus those who had not (36.3 percent), and among those who had been involved in a decision to stop or not start life support (55.0 percent) versus those who had not been (39.1 percent). The fourth relationship, between believing that dying people should have the right to ask and receive assistance to end their lives and directive completion, tended to be significant (p -value: 0.054).

Table 3 shows the results of the logistic regression analysis reporting adjusted odds ratios of having completed a directive versus planning or intending to complete one or not planning or intending to do so combined to indicate current noncompletion. The probability of having completed a personal directive was positively associ-

Table 2 / Additional End-of-life Research Question Findings in Relation to Advance Directives

	Total n* (%)	Directive completed %	Intend to complete %	No plan/ intention %	p-value**
Total	1,184	43.6	42.1	14.3	
Have had a close family member or friend pass away					<0.001
Yes	1,124 (95.0)	44.8	41.9	13.3	
No	59 (5.0)	20.3	47.5	32.2	
Have looked after or cared for a dying person					<0.001
Yes	604 (51.1)	50.7	39.2	10.1	
No	579 (48.9)	36.3	45.1	18.7	
Have been involved in a decision to stop or not start life support					<0.001
Yes	322 (27.4)	55.0	38.2	6.8	
No	855 (72.6)	39.1	43.9	17.1	
Believe dying people should have the right to ask and receive assistance to end their life early		n (%)	n (%)	n (%)	0.054
Yes	865 (77.6)	386 (44.6)	371 (42.9)	108 (12.5)	
No	249 (22.4)	103 (40.5)	100 (39.9)	46 (19.6)	

* Numbers do not add up to the total survey sample of 1,203 respondents because of missing values.

** Pearson χ^2

Table 3 / Adjusted Odds Ratios for Having or Planning an Advance Directive vs. Not Having and Not Planning an Advance Directive

	AOR*	95% CI** for AOR
Age (continuous)	1.05	[1.04; 1.06]
Marital status (vs. not married)		
Married	1.65	[1.24; 2.19]
Believe dying people should have the right to ask and receive assistance to end their life early (vs. no)		
Yes	1.47	[1.07; 2.02]
Have looked after or given care to someone who was dying (vs. no)		
Yes	1.36	[1.04; 1.76]

* Odds ratios adjusted for: age, sex, marital status, household size, believing dying people should have the right to ask and receive assistance to end their life early, have had a good friend or family member pass away, have looked after or given care to someone who was dying, have been involved in a decision to stop or not start life-support treatment.

** Confidence interval

ated with aging, marital status (married), the experience of having looked after or given care to someone who was dying, and the belief that dying people should have the right to ask for and receive assistance to end their lives.

DISCUSSION

As indicated, this population-based survey was designed to elicit information about the proportion of the general public in Alberta who had an advance directive and who had the intention to complete one or no intention of completing one, and also to determine which population subgroups were more or less likely to have completed

one. Although the findings of this survey cannot be generalized across Canada or to other countries, Canada is a particularly relevant country in which to study completion rates. Its healthcare system is publicly funded and offers free universal coverage of all medically necessary healthcare services at the point of delivery. To investigate completion rates among Canadians is thus to investigate public opinion on the importance of retaining autonomous decision-making rights when ill or dying — such opinion is not influenced by healthcare access issues associated with private charges and private insurance. The findings of this survey also highlight the state of public awareness of the need to be prepared for future healthcare decisions if one is seriously ill or dying.

The findings of a 43.6 percent rate of completion and a 42.1 percent rate of intention to complete demonstrate considerable public awareness and tacit approval of advance directives among the citizens of Alberta. The completion rate is much higher than the reported 2004 Canada-wide rate of 10 percent (1). Widespread support in Alberta for the 1997 *Personal Directives Act*, and the considerable discussion and educational efforts that have been undertaken since, could have resulted in a much higher rate in Alberta than in other provinces — although higher rates elsewhere are unlikely, as Alberta was the last province to develop advance directive legislation. It is possible, then, that other provinces will have a rate that is similar or higher.

The finding that aging was a factor for completion is not surprising, as older people have often been shown to have higher completion rates (9,

10, 12, 13, 16, 21, 22). There could be many reasons why older persons are the most likely to have completed a directive, but this study found select lived experiences to be highly significant for completion. This finding of the importance of lived experiences is similar to Siveira, Kim, and Lang's finding that more than half of all older persons with a directive had already needed to have major healthcare decisions made for them since they lacked the capacity to make such decisions due to a major illness (6). Life lessons learned through the illnesses of others — a recognition of the possibility of incapacity or death — may be a key factor in motivating people of all ages to complete an advance directive. A lack of significant life-and-death experiences may therefore help to explain why only one-tenth of younger adults (aged 18 to 24) had completed a directive as compared to 68.2 percent of persons aged 65 and over.

Future efforts and studies should focus on raising completion rates among younger adults. Past studies have also indicated this need. For example, in their study of medical, nursing, and other staff at a cancer centre, Go and colleagues (25) illustrated this need: they found that most had not completed a directive (25). Although the cancer centre staff knew that cancer and cancer deaths can occur among the young, this knowledge clearly did not prompt them to complete directives themselves. Younger people in good health who anticipate ongoing health and longevity tend not to feel the need for an advance directive. Death anxiety could be another factor for low completion rates among younger adults. Peck's study of oncology social workers found that this group had high death anxiety and an associated aversion to discussions of personal advance directives (26). Efforts to reduce death anxiety may therefore yield higher advance directive completion rates.

Another factor for low completion rates among younger persons generally and among some older persons could be that they believe that they will have time to prepare a directive when it becomes necessary. The finding that nearly as many Albertans were planning to complete a directive as had actually completed one could support this conclusion. Delays in completing advance directives are highly problematic, however, because sudden serious illness or injury can quickly render adults of all ages incapable of autonomous decision making.

It is therefore essential to have an advance directive available when you need it. The process of developing such a directive, as we now understand, is very important. Through this process, vital family/patient/caregiver discussions can

occur (1, 27). Even in Japan (as compared to other developed countries), where end-of-life care planning was not historically viewed as culturally appropriate, a recent survey of older adults conducted by Matsui showed that all persons who were supportive of developing and using advance directives were more likely to have discussed terminal care with their family members and physicians (28). Matsui's study is relevant in that it not only highlights the fact that directive preparation presents opportunities for important life-and-death discussions, but it also demonstrates that changes in culturally based end-of-life preferences and practices can and do occur over time. Advance directive completion rates can change considerably from one year to the next, indicating the need for ongoing monitoring.

Another finding of interest is that experiences with death and dying were identified as predictors of directive completion. Having had close family members or friends die, having provided care for such persons, having been involved in decisions to stop or not start life support, and believing that dying people should have the right to ask and receive assistance to end their lives were significantly related to directive completion. Each of these experiences and viewpoints would understandably have a great impact on individuals — likely greater than sociodemographic characteristics, which are often used to differentiate people. It is possible that many additional lived experiences and viewpoints influence directive completion. This could be a focus for future research.

If life-and-death experiences and viewpoints are important triggers for advance directive completion, they also present opportunities to raise completion rates. However, we must take great care in approaching people who have had a significant life event and encouraging them to complete a directive. We should recognize that it is highly unlikely that one discussion will lead to a written directive, as many people may only decide to complete a directive after having various life experiences — this is supported by the findings of our study. Follow-up discussions and direct assistance in completing a written directive may be needed to ensure that adults of all ages have one when it is needed (24).

CONCLUSION

Written advance directives, such as the one that Albertans can complete, are intended to ensure that an adult continues to exert independent influence over his or her personal healthcare decisions in times of incapacity. Apart from permitting the individual to specify the treatment he or she

wishes to have in the future — and, in Alberta's case, to select or reject surrogate decision makers — the process of completing a directive provides that person with the opportunity to have important conversations with family, friends, and healthcare providers (1, 27).

This population-based survey found a much higher than expected rate of completed advance directives among Albertans (43.6 percent); another large proportion of this population (42.1 percent) planned or intended to complete such a directive. Some select sociodemographic characteristics, notably aging, were associated with completion. In addition, this study found that people who had experienced some major end-of-life event or who had acquired certain end-of-life viewpoints were much more likely to have completed a directive. Lives lived and lessons learned should therefore be recognized as having a highly significant impact on directive completion. In light of this, it is not surprising that persons aged 18 to 24, single or never-married persons, and those who had never had a close family member or friend die were the least likely to have a directive and the most likely to have no plan or intention of completing one. They represent a key target group for education, as they are at risk of a sudden tragic accident or illness that could leave them vulnerable to a loss of decision-making capacity. In addition, 31.8 percent of older persons did not have a directive; they are another key target group, as they are at a higher risk of needing end-of-life care.

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