

# Planning for End-of-Life Care: Findings from the Canadian Study of Health and Aging\*

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## RÉSUMÉ

Les étapes utilisées pour l'officialisation des préférences en matière de soins en fin de vie et les facteurs en rapport avec ces étapes sont flous dans la documentation. À l'aide des données de la troisième phase de l'Étude sur la santé et le vieillissement au Canada (ESVC-3), nous avons examiné les relations entre les prédicteurs démographiques et en matière de santé, et les trois résultats (à savoir si les participants avaient réfléchi à leurs préférences de fin de vie, s'ils en avaient discuté, ou s'ils les avaient officialisées), et s'il y avait des relations entre les trois résultats. La région de résidence au Canada, le sexe féminin, et davantage d'années de scolarité étaient des facteurs associés à des personnes ayant réfléchi à leurs préférences. La région de résidence, le sexe féminin, et le manque de déficience cognitive étaient associés aux discussions en matière de préférences, et la région de résidence et le fait de ne pas avoir de conjoint étaient associés au dépôt de documents officiels. Les résidents de l'Ontario étaient les plus enclins à avoir réfléchi à leurs préférences, à en avoir discuté, et à les avoir officialisées, tandis que les résidents des Maritimes étaient les moins enclins à y avoir pensé et à avoir agi en conséquence. Enfin, avoir réfléchi à leurs préférences était associé au fait d'en discuter, et y avoir réfléchi et en avoir discuté étaient chacun associés à l'officialisation des préférences. Ces résultats correspondent au postulat que l'exécution du mandat (directive par procuration) est un processus comportant plusieurs étapes. Avoir une meilleure idée de ce processus peut se révéler utile lors de l'élaboration d'interventions visant à promouvoir la planification des soins en fin de vie.

## ABSTRACT

Steps involved in formalizing end-of-life care preferences and factors related to these steps are unclear in the literature. Using data from the third wave of the Canadian Study of Health and Aging (CSHA-3), we examined the relations between demographic and health predictors, on the one hand, and three outcomes, on the other (whether participants had *thought about*, *discussed*, or *formalized* their end-of-life preferences), and considered, as well, whether relations existed among the three outcomes. Canadian region of residence, female gender, and more years of education predicted having thought about preferences; region of residence, female gender, and lack of cognitive impairment predicted discussion of preferences; and region of residence and not being married predicted whether formal documents were in place. Ontario residents were most likely to have thought about, discussed, and formalized their preferences, whereas Atlantic residents were least likely to. Finally, having thought about preferences was associated with discussion, and having thought about and having discussed preferences were each associated with formalization of preferences. These findings are in keeping with the position that Advance Directives (AD) execution is a multi-stage process. A better understanding of this process may prove useful for the development of interventions to promote planning for end-of-life care.

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Advance directives (ADs) are written documents that allow individuals to specify their medical care preferences and/or legally to appoint a surrogate decision maker (Moore & Sherman, 1999). Such directives assist individuals, families, medical personnel, and the legal system in making appropriate decisions regarding an individual's health, should the need arise ("Advance directives (editorial)," 1992; Cramer, Tuokko, & Evans, 2001). With the anticipated growth in the proportion of older adults (60 years and over) in Canada (from 15.5% in 1990 to 26.7% in 2031 [United Nations, 1995]), it is becoming increasingly important that such mechanisms be available and be used. ADs are an important component of advance care planning, allowing individuals to outline what their health care wishes are should they become incapacitated.

Regardless of the potential advantages, completion rates vary widely for older adults (19 to 62%) (see, e.g., Braun, Onaka, & Horiuchi, 2001; Cramer et al., 2001; Ditto et al., 2003; Hopp, 2000; Kahana, Dan, Kahana, & Kercher, 2004). In an effort to increase AD completion, the U.S. government implemented the Patient Self-Determination Act (PSDA) in 1990, which requires health care providers to educate patients and staff about a patient's right to either refuse or accept medical treatment and to record whether patients have ADs in place (Patient Self-Determination Act, 1990). In Canada, no such initiative as the PSDA exists. Canadian provinces did not concurrently adopt legislation on the use of ADs, nor is there federal legislation. Nearly all provinces adopted their own statutes between 1990 and 2000, although New Brunswick has yet to adopt legislation. Provincial governments that have adopted AD legislation provide publicly accessible information on ADs that

describes what is involved in an AD and how to complete one and promotes the advantages of having ADs in place (e.g., Ontario, 1992). Legislation is also functionally similar across provinces; each provides for both proxy (i.e., specifying who you wish to make health care decisions for you if necessary) and instructional (i.e., outlining what types of care health care providers may give) directives, despite minor differences in how these directives are handled (Browne & Sullivan, 2006). However, given differences in when legislation was implemented across provinces, it is plausible that provincial differences in the likelihood of completing ADs may exist. To our knowledge, no studies have examined provincial differences in frequency of executing ADs in Canada.

To understand AD completion rates better, researchers have examined the characteristics of those who complete ADs. Some studies show that greater age (Cramer et al., 2001; Levin et al., 1999; McAuley & Travis, 2003; Moody, Small, & Jones, 2002; Rosnick & Reynolds, 2003), more education (Cramer et al., 2001; High, 1993; Hopp, 2000; McAuley & Travis, 2003; Moody et al., 2002), increased memory impairment and dementia (McAuley & Travis, 2003), gender (Moody et al., 2002), poorer health (Rosnick & Reynolds, 2003), and marital status (Moody et al., 2002) are all associated with increased probability of completion of various types of ADs. Conversely, other studies have found that age (Hopp, 2000), cognitive impairment (Cramer et al., 2001; Levin et al., 1999; Rosnick & Reynolds, 2003), gender (Levin et al., 1999; McAuley & Travis, 2003; Moody et al., 2002), and health (Hopp, 2000; Rosnick & Reynolds, 2003) show no association with completion of ADs.

Beyond AD completion, thinking about and discussing care preferences may also be important. As a preliminary step, thinking earnestly about one's care preferences may provide an impetus for further dialogue with physicians and surrogates to help ensure care preferences are understood and followed upon incapacitation. To our knowledge, only one study (Lo, McLeod, & Saika, 1986) has examined whether people had *thought* about their preferences for surrogate decision makers, and this study was conducted prior to implementation of the PSDA. Older patients were found more likely than younger patients to have thought about surrogate decision makers; no other medical (e.g., recent hospitalization), functional (e.g., climb flight of stairs), psychosocial (e.g., feeling depressed), or demographic (e.g., sex, completion of high school) factors were significantly predictive.

Several studies, however, highlight the importance of discussion between patients and their clinicians/surrogates (Bradley, Peiris, & Wetle, 1998; Covinsky et al., 2000; Golin et al., 2000; Inman, 2002; Sansone & Phillips, 1995; Sulmasy et al., 1998). Numerous observers argue that, although in intention the PSDA was an appropriate approach to increasing AD completion, it has done little to ensure that preferences are actually communicated to, and followed by, health care professionals and other surrogates (e.g., Teno et al., 1997; see Covinsky et al., 2000). For example, using data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), a large multi-site study intended to describe end-of-life care, Teno et al. (1997) found that the PSDA significantly increased the amount of AD documentation for those with existing ADs, but that communication between physician and patient regarding ADs did not improve. Wenger et al. (2000) noted that only 46 per cent of physicians understood patient preferences to forgo CPR; unsurprisingly, better communication and a lengthier relationship with the patient were associated with a better understanding of preferences. Similarly, Marbella, Desbiens, Mueller-Rizner, and Layde (1998) observed that half of surrogates believed patients wanted to be resuscitated when they actually did not. Promisingly, Sulmasy et al. (1998) found that, if patients had spoken to their surrogates about health care preferences, surrogate judgement was 1.9 times more likely to reflect patient preferences accurately than in the case of those who had not spoken to their surrogates.

However, few studies have examined factors that relate to discussion of preferences between patient and physician/surrogate. For example, using SUPPORT data, Golin et al. (2000) found that male

gender and higher frequency of hospitalization (i.e., poorer health) were the only demographic or health factors associated with communication about resuscitation preferences with physicians; age, marital status, and education (among other factors) were not related. Similarly, Hofman et al. (1997) also observed that poorer health and prognosis predicted discussion of care preferences with a physician. Similar to findings from the AD completion literature, these results suggest poorer health is an important predictor of discussion of care preferences.

Hofman et al. (1997) and Golin et al. (2000) also found that discussion of care preferences was related significantly to already having an AD in place, suggesting profitable links between the two. It is unclear, however, how thinking of one's end-of-life preferences relates ultimately to both discussing and completing ADs. There are certainly no guarantees that thinking about preferences relates to discussion or AD completion, or that discussion relates to AD completion. In fact, as noted above, physicians and other surrogates often have a poor understanding of patient preferences, even when those preferences are formalized in an AD (e.g., Marbella et al., 1998; Wenger et al., 2000). Examining systematically the probability that one will occur given that the other has is necessary to gauge the strength of relations that may exist between thinking about, discussing, and formalizing AD preferences.

In the current descriptive study, using existing data from the CSHA-3, we examined frequencies of participants who (a) had thought about who they would want as a surrogate decision maker, (b) had discussed their preferences for end-of-life care with someone, and (c) had put a formal legal document in place. We then investigated the relations among several demographic and health variables and each of the three AD-related measures. In three logistic regression models, we analysed the predictive utility of Canadian region of residence, gender, marital status, age, education, and health in relation to each of the three AD measures. For the second and third models, we also investigated whether having thought about end-of-life preferences was related to having discussed end-of-life preferences or to AD completion. And, in a subsequent analysis, we investigated the extent to which discussion of preferences was associated with AD completion.

## Method

### Procedure

The sample for the current study was obtained from the Canadian Study of Health and Aging (CSHA), a

nation-wide, multi-centre longitudinal study of cognitive impairment and aging in adults aged 65 or older. Those participants who took part in the screening interview component of the CSHA-3—which included questions concerning demographic characteristics of the participants, health status, and health care preferences—were selected initially for this study (i.e., 3,334 of the original 9,008 community-dwelling participants seen in the CSHA-1).

To understand fully the nature of the participants in this study, it is important to note that the sample selected at CSHA-1 was a representative sample of people aged 65 and over who were randomly chosen from medicare lists in nine provinces or from the Enumeration Composite Record in Ontario. Equivalently sized sub-samples were selected within each of five Canadian regions (Atlantic provinces, Quebec, Ontario, Prairie provinces, British Columbia). To take part in the study, all participants were required to speak either English or French.

In each wave of the CSHA, participants were screened for cognitive impairment (3MS; Teng & Chui, 1987). Only people showing cognitive impairment and a sub-sample of those without cognitive impairment took part in clinical examinations (neuropsychological and medical) designed to confirm the presence of cognitive impairment and arrive at a differential diagnosis.

At CSHA-3, all those who received clinical examinations at CSHA-1 or -2 (1996–1997) again underwent clinical examinations. Those participants in CSHA-3 who did not receive clinical examinations at CSHA-1 or -2 and who scored greater than or equal to 50 but less than 90 on the CSHA-3 screening 3MS (Teng & Chui, 1987) underwent a neuropsychological examination; those demonstrating cognitive impairment and a sub-sample of those without cognitive impairment then underwent a medical examination. Subsequently, a multidisciplinary consensus diagnosis of *no cognitive impairment* (NCI), *cognitive impairment no dementia* (CIND), or *dementia* was made using the same procedures as in CSHA-1 and CSHA-2 (Canadian Study of Health and Aging Working Group, 1994; Tuokko, Kristjansson, & Miller, 1995). Dementia was diagnosed using criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed., rev.) (American Psychiatric Association, 1987).

At CSHA-3, all those who scored greater than 90 on the 3MS and so might not have received any clinical examinations were considered to have NCI and were categorized as such in the current paper. Overall, 2,564 participants had complete data (see below) and

were selected for use in the current analyses. A more comprehensive explanation of overall CSHA methods can be found elsewhere (McDowell, Xi, Lindsay, & Tuokko, 2004).

### Participants

At CSHA-3, participants remained evenly distributed across the five regions of Canada: 18.0 per cent were from the Atlantic provinces (i.e., Prince Edward Island, Nova Scotia, New Brunswick, Newfoundland/Labrador;  $n=462$ ); 18.9 per cent from Quebec ( $n=486$ ); 20 per cent from Ontario ( $n=513$ ); 21.6 per cent from the Prairie provinces (i.e., Alberta, Saskatchewan, Manitoba;  $n=555$ ); and 21.6 per cent from British Columbia ( $n=555$ ). Participants' ages ranged from 75.25 to 102.37 years ( $M=82.41$ ,  $SD=5.02$ ), and level of education ranged from 0 to 33 years ( $M=11.05$ ,  $SD=3.80$ ). Females accounted for 61.2 per cent of the sample ( $n=1,569$ ), and married people accounted for 43.6 per cent ( $n=1,117$ ). With reference to health, 85.6 per cent of the sample rated their health "these days" as either *very good* or *pretty good* ( $n=2,194$ ); the majority of participants (61.4%) rated their health "compared to a year ago" as *about the same* ( $n=1,575$ ), and 21.4 per cent rated it as *somewhat worse* ( $n=548$ ). Regional proportions and demographic information by each dependent variable can be found in Table 1.

### Measures

We employed three dichotomous dependent variables ( DVs) in the current study: (a) "Have you thought about who would make health decisions for you if you were unable to do this for yourself?" (b) "Have you discussed your preferences for end-of-life care with anyone?" and (c) "Have you formalized this in a legal document (e.g., a living will or a Power of Attorney for Personal Care)?" Data on all three were coded as either *no* (=0) or *yes* (=1). For the first and second DVs,  $n=2,564$  participants had complete data. However, only those who answered *yes* to having discussed their preferences with someone (i.e., the second DV) were asked whether they had a formal document in place (i.e., the third DV;  $n=1,491$ ). This restriction was in place because it was assumed that preferences would necessarily have to be discussed with someone (even if only a lawyer or notary) to be formalized in a document. Thus, data for  $n=2,564$  participants was available on the first two DVs, and for  $n=1,491$  participants on the third DV.

Years of age was calculated as the exact number of days from date of birth to interview date and then converted into exact years to two decimal places. Diagnostic status (i.e., diagnosis of NCI,



**Table 1: Proportions answering yes and no to each of the three dependent measures<sup>a</sup>**

		DV #1: Have you thought about who would make health decisions for you if you were unable to do this for yourself?			DV #2: Have you discussed your preferences for end-of-life care with anyone?			DV #3: Have you formalized your wishes in a legal document?		
		Yes	No	Total	Yes	No	Total	Yes	No	Total
Region										
Atlantic	%	74.84	25.16	100.00	46.42	53.58	100.00	55.61	44.39	100.00
	n	345	116	461	214	247	461	119	95	214
Quebec	%	80.21	19.79	100.00	54.43	45.57	100.00	62.88	37.12	100.00
	n	389	96	485	264	221	485	166	98	264
Ontario	%	91.18	8.82	100.00	68.82	31.18	100.00	84.90	15.10	100.00
	n	465	45	510	351	159	510	298	53	351
Prairies	%	84.84	15.16	100.00	58.30	41.70	100.00	63.47	36.53	100.00
	n	470	84	554	323	231	554	205	118	323
B.C.	%	83.75	16.25	100.00	61.19	38.81	100.00	61.06	38.94	100.00
	n	464	90	554	339	215	554	207	132	339
Total Sample	%	83.19	16.81	100.00	58.15	41.85	100.00	66.73	33.27	100.00
	n	2133	431	2564	1491	1073	2564	995	496	1491
Gender	% female	62.00	57.10	61.20	65.30	55.50	61.20	65.60	64.50	65.30
Marital Status	% married	44.20	40.60	43.60	42.30	45.30	43.60	40.30	46.40	42.30
Diagnostic Status	% NCI	79.00	74.71	78.30	80.82	74.74	78.30	79.90	82.66	80.80
	% CIND	17.00	19.49	17.40	15.96	19.38	17.40	16.78	14.31	16.00
	% demented	4.00	5.80	4.30	3.22	5.87	4.30	3.32	3.02	3.20
Age	M	82.32	82.88	82.41	82.34	82.51	82.41	82.53	81.98	82.34
	SD	4.99	5.14	5.02	5.05	4.99	5.02	5.17	4.77	5.05
Education (years)	M	11.21	10.24	11.05	11.25	10.77	11.05	11.33	11.07	11.25
	SD	3.77	3.87	3.80	3.75	3.86	3.80	3.69	3.86	3.75
Health these days?	M	4.08	4.06	4.08	4.09	4.07	4.08	4.11	4.04	4.09
	SD	0.70	0.69	0.70	0.69	0.70	0.70	0.69	0.68	0.69
Health compared to a year ago?	M	2.92	2.94	2.93	2.92	2.93	2.93	2.93	2.90	2.92
	SD	0.77	0.79	0.77	0.79	0.75	0.77	0.79	0.81	0.79

<sup>a</sup> Regional proportions and samples sizes reflect within-region values. Values for gender, marital status, diagnostic status, age, education, and health are based on the entire available sample for each dependent variable ( $n = 2,564$  for DVs #1 and #2;  $n = 1,491$  for DV #3). Per cent values for gender reflect the proportion of those who said yes on a given DV to female; for marital status, reflect the proportion of those who said yes on a given DV to married; and for diagnostic status reflect the proportion of those who said yes or no on a given DV to no cognitive impairment (NCI), cognitive impairment no dementia (CIND), or dementia.

CIND, or dementia) was used as a measure of cognitive impairment. Finally, as measures of health status, we selected participants' ratings on screening examination questions concerning their health "these days," ranging from *very poor* (= 1) to *very good* (= 5); and health "compared to a year ago," ranging from *much worse* (= 1) to *much better* (= 5).

*Analytic Strategy*

In separate logistic regression models, each of the three dependent variables was regressed on the set of eight independent variables: region of residence, gender, marital status, diagnostic status, age, years of education, and self-reported health ("these days" and "compared to a year ago"). Whether participants had thought about who they would like to make

end-of-life health care decisions for them was also entered as a predictor for the models where "discussed it?" and "Formalized document in place?" served as dependent variables (DVs). This allowed us to investigate whether thinking about preferred surrogates served as an effective preliminary step in discussing and completing ADs. We could not analyse the predictive effect on AD completion of having discussed care preferences because, in the current study, only those who reported having discussed their preferences were asked if they had an AD in place. This rendered the discussion variable a constant when predicting AD completion, and thus the predictive effect of the one on the other could not be analysed within the model. We did, however, analyse the relation between discussion and AD completion in a subsequent  $\chi^2$  analysis.

As region of residence (five-level) and diagnostic status (three-level) were categorical variables, post hoc pair-wise comparisons were necessary to examine region and diagnostic-status group differences on each DV. In light of arguments against the use of Bonferroni correction in cases of inflated type-II error (e.g., Aickin & Gensler, 1996), we decided a priori to adjust *p*-values for multiple comparisons based on Holm's (1979) method. Holm's method is less conservative and thus necessarily more powerful than the traditional Bonferroni approach (Aickin & Gensler, 1996; Shaffer, 1995). As opposed to simply multiplying each comparison's *p*-value by the total number of comparisons (i.e., the Bonferroni approach), Holm's (1979) method involves (a) rank-ordering *p*-values for all comparisons from smallest to largest; (b) adjusting *p*-values, where each *p*-value is multiplied by (*n* - *i* + 1), where *n* = the total number of comparisons and *i* = rank of a given *p*-value; (c) in order of initial *p*-value rank, comparing each adjusted *p*-value to our set alpha level of 0.05; and (d) specifying that once one non-rejection is found, all succeeding comparisons are automatically considered non-significant. Given that the probability of rejecting the null hypothesis increases with successive comparisons (as adjusted *p*-values become less conservative), Holm's (1979) method can never reject fewer comparisons than the Bonferroni method.

**Results**

Overall, we found that the majority of the 2,564 participants had thought about who they would want to make decisions for them (*n* = 2,133; 83.19%) and had discussed their preferences with someone (*n* = 1,491; 58.15%; see Table 1). However, of the 58.15 per cent who had discussed their preferences (*n* = 1,491) and were thus asked if they had formalized an AD, only 66.73 per cent (*n* = 995) had done so (amounting to 38.81% of the total sample). Regional proportions can also be found in Table 1. In the analyses below, we elaborate on the relations between thinking about, discussing, and formalizing an AD, as well as on the importance of regional differences when examining the three AD-related measures.

*Logistic Regressions*

A series of logistic regressions were run on the current data, to predict each of the three dichotomous outcomes. The full available sample was employed when analysing outcomes 1 and 2 (*n* = 2,564); only those with data on formal documents were used for outcome 3 (*n* = 1,491). See Table 2 for model results. We found no evidence for multicollinearity among predictors in any of the three models (all variance

**Table 2: Logistic regression models for each dependent variable of interest<sup>a</sup>**

Predictor	DV #1. Have you thought about who would make health decisions for you if you were unable to do this for yourself?				DV #2. Have you discussed your preferences for end-of-life care with anyone?				DV #3. Have you formalized your wishes in a legal document?								
	B	Wald	p	OR	95% CI	B	Wald	p	OR	95% CI	B	Wald	p	OR	95% CI		
Region of Residence	—	40.19	< 0.001	—	—	—	29.96	< 0.001	—	—	—	64.16	< 0.001	—	—		
Gender	0.38	9.60	< 0.001	1.47	1.15	1.87	0.41	17.14	< 0.001	1.51	1.24	1.84	0.30	0.58	0.93	0.71	
Marital Status	0.21	2.56	0.11	1.23	0.95	1.58	-0.05	0.23	0.63	0.95	0.78	1.16	4.40	< 0.05	0.75	0.57	
Dx Status	—	1.48	0.48	—	—	—	—	11.80	< 0.01	—	—	—	0.94	0.61	—	—	
Age	-0.02	2.31	0.13	0.98	0.96	1.01	0.00	0.00	0.96	1.00	0.98	1.02	2.05	0.15	1.02	0.99	
Education	0.05	12.06	< 0.001	1.06	1.02	1.09	0.01	0.39	0.53	1.01	0.98	1.03	1.16	0.28	1.02	0.99	
Health these days?	0.05	0.38	0.54	1.05	0.90	1.23	0.02	0.14	0.71	1.02	0.90	1.17	2.16	0.14	1.14	0.96	
Health compared to a year ago?	-0.09	1.61	0.20	0.91	0.79	1.05	-0.05	0.71	0.40	0.95	0.85	1.07	0.17	0.68	1.03	0.89	
Thought about who?	—	—	—	—	—	—	1.92	219.43	< 0.001	6.80	5.28	8.76	1.01	19.07	< 0.001	2.73	1.74

<sup>a</sup> DV = dependent variable; Dx status = diagnostic status; "Thought about who?" = DV #1 entered as a predictor. Region of residence and dx status are categorical variables; rather than specify a reference group and report values for each dummy coded variable to represent the effects, Wald and *p*-values represent omnibus tests. Specific regional and diagnostic group differences were captured using subsequent Holm's (1979) corrected pair-wise comparisons (reported in "Results" section).

inflation factor values <2.00). Only reliable predictors are noted below.

*DV #1: "Have you thought about who would make health decisions for you if you were unable to do this for yourself?"* Females were 1.46 times as likely as males to have thought about preferred surrogates. Increasing years of education reliably predicted whether participants had thought about a preferred surrogate ( $OR=1.06$ ). Region of residence was also predictive. Pair-wise comparisons revealed that Ontario residents were significantly more likely to have thought about their end-of-life care preferences than residents of any other Canadian region (i.e., Atlantic [ $OR=3.27$ ], Quebec [ $OR=2.27$ ], Prairies [ $OR=1.83$ ], British Columbia [ $OR=2.09$ ]). Also, those from the Prairies ( $OR=1.79$ ) or British Columbia ( $OR=1.57$ ) were more likely than those from the Atlantic region to have thought about preferred surrogates (all Holm's [1979] corrected  $ps < 0.05$ ).

*DV #2: "Have you discussed your preferences for end-of-life care with anyone?"*

Females were 1.51 times as likely as males to have discussed their end-of-life care preferences with someone. Diagnostic status was predictive; those diagnosed with NCI were 1.96 times as likely as those with dementia to have discussed their preferences, but no differences were evident between NCI and CIND groups, or CIND and dementia groups. Having thought about end-of-life care preferences was also highly predictive of having discussed those preferences ( $OR=6.80$ ). With regard to region of residence, Ontarians were more likely than those from the Atlantic ( $OR=2.59$ ), Quebec ( $OR=1.86$ ), or the Prairies ( $OR=1.67$ ) and those from British Columbia were more likely than Atlantic residents ( $OR=1.78$ ) to have discussed their preferences (all Holm's [1979] corrected  $ps < 0.05$ ).

*DV #3: "Have you formalized your wishes in a legal document?"*

Married/common-law participants were less likely ( $OR=0.75$ ) than unmarried participants to have a formal AD in place, and having thought about one's preferences was also reliably predictive ( $OR=2.73$ ). Region of residence was again predictive. Ontarians were more likely than those from all other regions (i.e., Atlantic [ $OR=4.56$ ], Quebec [ $OR=3.18$ ], Prairies [ $OR=3.27$ ], British Columbia [ $OR=3.60$ ]) to have a formal document in place (all Holm's [1979] corrected  $ps < 0.05$ ); no other regional differences were observed.

### Zero-order $\chi^2$ Relation between Having Discussed and Formalized End-of-Life Care Preferences

Using zero-order  $\chi^2$ , we found that, of those who had discussed their preferences ( $n=1,491$ ), a greater proportion had also formalized their preferences (66.73%) than of those who had not formalized their preferences (33.27%;  $\chi^2(1, N=1,491)=167.00$ ,  $p < 0.001$ ). Although we could not analyse this relation in the logistic model above, given linear redundancy between the two variables (i.e., due to the format of the questionnaire used in the current study, only those who had discussed their preferences were asked whether they had formalized their preferences), this zero-order analysis provides an preliminary examination of the relation between the two variables.

## Discussion

Using a large, nation-wide data set, the current, descriptive study found that the majority of participants had thought about who they would want to make decisions for them and had discussed their preferences with someone. A majority of those who discussed their preferences also formalized their preferences in a legal document, but this proportion accounted only for a minority of the entire sample. Notably, the proportion that had discussed their preferences with someone exceeded the proportion in several previous studies of older adults (Cramer et al., 2001; Gamble, McDonald, & Lichstein, 1991; Hopp, 2000; Kahana et al., 2004; Levin et al., 1999), although one study reported a larger proportion (Inman, 2002). The number of participants who had formalized their preferences also exceeded numbers in some previous reports (Cramer et al., 2001; Hopp, 2000) but was similar to or lower than those in others (Braun et al., 2001; Inman, 2002; Kahana et al., 2004).

That the proportions of those discussing and formalizing their preferences were, overall, higher than previous results would have led us to expect may have been due to the fact that data for the current study were derived from the third wave of a longitudinal study. Those seniors who remained participants after 10 to 12 years of involvement could be considered "survivors," who may have had more time to think about and act upon their preferences for end-of-life care than did those who needed, or desired, to make such decisions at younger ages. Another contributing factor may have been that, in the last several years in Canada, there have been many efforts to enhance public awareness of end-of-life issues, such as the 1995 (Senate of Canada, 1995) and 2000 (Carstairs & Beaudoin, 2000) Senate subcommittee reports on end-of-life care, which received

national media coverage. It is plausible that, by CSHA-3, many seniors had had exposure to this coverage and consequently had proceeded to think about and act upon their end-of-life care preferences.

Separate logistic models revealed that region of residence, female gender, and more years of education were associated with a higher probability of having thought about who participants would want to make end-of-life treatment decisions for them. Whether participants had discussed their preferences with someone was predicted by region of residence, diagnostic status, and having thought about who they would want as a decision maker. Finally, region of residence, marital status, and having thought about who they would want as a decision maker predicted whether formal documents were in place.

The impact of individual predictors across DVs both contradicted and supported extant literature. In the current study, females were more likely than males to have thought about and discussed their end-of-life care preferences, but sex groups did not differ on whether they had formalized their care preferences. Contrary to our findings, Lo et al. (1986) did not find sex differences on having thought about care preferences, although their study employed a middle-aged sample and was conducted prior to the implementation of the PSDA in the United States. Therefore, our findings may not be comparable because our sample employed older adults ( $M = 82.41$  years) and our data were collected after most provinces had adopted AD legislation. With regard to discussion of care preferences, Golin et al. (2000) found that *males* were more likely to have communicated with their physicians regarding resuscitation preferences, but the authors' sample was again much younger ( $M = 59$  years) than in the current study. And, in line with our findings, most available studies find little or no sex differences on having formalized care preferences (e.g., Levin et al., 1999; McAuley & Travis, 2003; Moody et al., 2002). Thus, although we found sex differences on having thought about and discussed care preferences in our data, sex differences were not apparent as to when preferences were formalized. Future research should investigate why females do not formalize their preferences, despite having thought about and discussed their preferences to a greater extent than have males.

Not being married predicted formalization of preferences but did not predict thinking about or discussing preferences. Few studies have analysed marital status in this context. One available study (Moody et al., 2002) found that marital status predicted having a living will within a nursing home sample of older adults similar in age ( $M = 81.50$  years) to the current

sample, although the direction of the marital status effect is unclear from their results.

With regard to diagnostic status, it seems counter-intuitive that fewer cognitively impaired participants in our sample had discussed their preferences and that diagnostic groups did not differ on having thought about care preference or having put in place formal care preferences. Similarly, we found no effect of self-reported health on having thought about, discussed, or formalized preferences. Previous research supports the position that *increased* cognitive impairment or dementia (McAuley & Travis, 2003) and poor health or deterioration of functioning (Patterson, Baker, & Maeck, 1993) are likely harbingers of end-of-life care planning. But, self-report of end-of-life care planning by seniors with cognitive impairment is difficult to validate, given inherent problems with long-term recall in those participants with dementia or memory impairment. Further studies are required before determinations regarding links between diagnostic status and end-of-life care planning can be made.

Despite overwhelming evidence that greater age is associated with end-of-life care planning, we did not find any age effects in the current study. This finding may be explained partially by a truncation of age range in our sample, as participants were all 75 years or older ( $M = 82.41$  years). It is plausible that, on average, those seniors who are older (e.g., 75 years or older) are all equally as likely to have thought about, discussed, and formalized their end-of-life care wishes. This notion is supported by Hopp (2000), who demonstrated that, in a sample of 520 seniors aged 70 years and older, no differences in having an informal discussion of preferences, a living will, or a durable power of attorney for health care existed between the youngest (70–74 years) and oldest (85+ years) age groups. Studies employing broader-aged samples appear more likely to demonstrate age effects (e.g., Cramer et al., 2001; Levin et al., 1999; Rosnick & Reynolds, 2003), and such effects may be reflective of greater age-related variance in end-of-life care planning across the range of participants.

The education effect seen in our study was inconsistent with previous research. Although we found that education was highly predictive of having thought about preferred surrogate decision makers, we did not find that education predicted having either discussed or formalized those preferences. This suggests that greater education may predict an important first step in end-of-life care planning but not more direct steps toward formalizing care end-of-life preferences. Conversely, several studies (Cramer et al., 2001; High, 1993; Hopp, 2000; McAuley & Travis, 2003;



Moody et al., 2002) have identified greater education as a significant predictor of having an AD in place, although little research has considered education in the context of having thought about and discussed one's preferences. Given that the range of education at CSHA-3 was quite broad relative to that in previous studies ( $M = 11.05$ ,  $SD = 3.80$ ,  $range = 0-33$ ), it remains unclear why education did not predict having a formal document in place. Albeit those with more education may be more aware of, and be better able to understand and pay for, end-of-life care documents/legislation relative to those who are less educated (Cramer et al., 2001; High, 1991), greater education did not yield the formalization of care preferences in the current sample. Future studies should investigate this effect further in population-based, broadly educated samples to clarify the role of education in advanced care planning.

Our analysis of end-of-life care differences across Canadian regions revealed that Ontario seniors were most likely to have thought about, discussed, and formalized their preferences; seniors from Atlantic Canada were least likely to have either thought about or discussed their preferences. These regional differences cannot be explained by time since implementation of provincial legislation. Although Ontario (1992) has had provincial legislation regarding ADs longer than many provinces, Quebec (1990) has had legislation even longer; yet Quebec residents were less likely than Ontarians to have thought about, discussed, or formalized their preferences. Further, Newfoundland (1995) and Nova Scotia (1989) implemented legislation before other provinces (e.g., Alberta, 1997; British Columbia, 1996); yet participants from the Atlantic region were consistently least likely to have thought about, discussed, or formalized end-of-life care preferences. Given that ours is the first study to analyse Canadian regional differences in thinking about, discussing, and completing ADs, further research is required to identify key factors contributing to these regional differences. For example, it will be important to investigate the impact of regional differences on support for AD completion, pervasiveness of AD knowledge among citizens, and efficacy of educational initiatives regarding ADs. In the meantime, we offer the current results as a starting point from which future studies examining regional differences may proceed.

Finally, we found evidence that having thought about end-of-life care preferences was associated with discussion of preferences and that thinking about and discussing preferences were each associated with formalization of preferences. This finding is in keeping with the position of Havens (2000, 2001) that AD execution is a multistage process, with completion of

an AD document as only one of the steps. The theoretical model she proposed to study the execution of ADs (by 210 community-dwelling adults 18 years of age and older with decisional capacity) incorporated the concepts of personal autonomy, moral communities, and stages of change derived from the Transtheoretical Model of Behaviour Change (Prochaska & Velicer, 1997). She found that those participants who had completed ADs (38 respondents) had participated in more physician-initiated discussions about ADs, had more numerous AD educational experiences, more personal experiences with the terminal illness or critical injuries of relatives or friends, and a greater degree of familiarity with AD documents than had those who had not completed ADs. From her results and ours, it appears that, prior to formalizing ADs, individuals engage in a developmental process of end-of-life decision making whereby experiences (e.g., discussions with others) promote movement toward informed choices.

As with most studies, the results of our research must be interpreted with caution. Our sample was comprised of Canadian individuals over age 75 who spoke either English or French and were taking part in the third wave of a longitudinal study of health and aging. This lack of diversity (i.e., cultural and racial) is likely to have resulted in larger proportions of the sample's responding positively to our questions than might have been the case if our sample had shown greater cultural and racial diversity. Another limitation of our study is that the way in which the questions were asked does not allow us to examine the correspondence between the answers to questions 1 and 2. That is, we could not ascertain whether they had discussed their preferences with the person they thought about wanting as their decision maker. Also, it was not feasible to evaluate the presence of interactions amongst predictors in our logistic models, given the inordinately large number of terms that would have to be added to each model (e.g., for two-way interactions only, dozens of additional terms are required for each model). So many interactions in a model at once is not only particularly difficult to interpret but also can introduce substantial multi-collinearity into the model. We argue that, although some information may be gained from evaluating interaction terms concurrently, the utility of this approach is limited in the present context.

Given these limitations of our research and the relatively limited research available examining the processes involved in planning for end-of-life, we support Havens (2001) in proposing that future research focus on more clearly identifying the preliminary stages and processes involved in moving toward

completion of formal AD prior to the onset of illness. Although her research and ours suggests that using the conceptual framework provided by the Transtheoretical Model of Behaviour Change may be useful in this regard, other social-psychological frameworks, such as the Theory of Planned Behaviour (Ajzen, 1991), may also prove fruitful. In addition to providing conceptual explanations of the process of AD completion, both of these frameworks have proved useful in the development of interventions for facilitating health behaviour change (e.g., Sutton, 2002). Their application within the field of planning for end-of-life care may inform future attempts to promote the communication of end-of-life preferences, whether through AD completion or by other means.

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