# The Preferred Place of Last Days: Results of a Representative Population-Based Public Survey

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#### **Abstract**

*Background:* The place of death is of considerable interest now, yet few studies have determined public preferences for place of end-of-life (EOL) care or final days of life.

*Objective:* A survey was designed to answer three questions: (1) What are public preferences for the place of last days? (2) Is this place preference related to socio-demographic and other background characteristics? and (3) Is this place preference associated with specified previous death and dying experiences, the preparation of a living will or advance directive, or a viewpoint supportive of death hastening?

*Design:* An experienced telephone survey company was commissioned to gain a representative population-based sample and survey participants. In mid-2010, 1203 adults were surveyed in Alberta. Descriptive statistics and multinomial logistic regression were conducted.

**Results:** This survey revealed 70.8% preferred to be at home near death; while 14.7% preferred a hospice/palliative care facility, 7.0% a hospital, and 1.7% a nursing home; 5.7% had no stated preference. Marital status was the only predictor of place preference, with widowed persons more often indicating a preference for a hospital or hospice/palliative care facility.

Conclusions: These findings suggest homes are the preferred EOL place now for the majority of Albertans, if not other citizens, while at the same time suggesting that marital and living arrangement realities temper EOL place choices and possibilities, with widows best realizing the need for assistance from others when dying. The widespread preference for home-based EOL care indicates public health interventions are needed to promote good home deaths.

#### Introduction

The location or place of death is of considerable interest worldwide. Not only does the place of death or end-of-life (EOL) care impact the quality of death and dying, but there are many direct and indirect costs and other considerations associated with the place of death and dying. Although much has been made of the high cost of dying in hospitals and nursing homes, home-based dying often involves significant out-of-pocket costs in addition to difficult tasks and responsibilities for family caregivers. Host EOL care in the home is provided by family caregivers, often with little assistance from others, including formal home care providers. Regardless, a shift from hospital to home-based death and dying is occurring in Canada and elsewhere, notably Britain and the United States.

until the place of EOL care becomes the focus of attention over place of death, major EOL issues such as inadequately supported home-based dying will not be addressed.

This concern is particularly relevant now that studies are finding terminally ill people and their family members often state a preference for home deaths. It is also evident that some home deaths are not possible because of factors such as burdens associated with caring for dying loved ones at home. Regardless, having a place preference is often possible now, as most deaths occur in adulthood and following evident declining health. With most deaths "expected" now, this potential to anticipate death provides more opportunities to plan ahead and thus enhance the possibility of achieving the preferred place of final days. From a public health perspective, it is critically important to take public preferences into account when developing EOL care strategies.

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#### Literature review

Few studies have determined population-based preferences for place of death, dying, or final days of life. A multiple database search revealed only two public surveys. A populationbased survey in Australia determined factors associated with preferred death place, with 2657 respondents asked to imagine they were dying of a terminal illness.<sup>17</sup> This study revealed 70% wanted at the time of death to be at home, 19% in hospital, 10% in a hospice, and 1% in a nursing home. <sup>17</sup> Six factors predicted a home death preference: younger age, male, born in Ireland/UK or Italy/Greece, better physical health, poorer mental health, and having few concerns about home deaths. <sup>17</sup> A more recent public survey was conducted in Japan to clarify preferences among representative 40-79 year-olds for place of death and EOL care. 18 Among the 1042 respondents, 44% preferred the home. 18 Three factors for this preference were identified: having experienced the home death of a relative, knowing about home care nursing, and having insurance coverage for 24-hour skilled home palliative services. 18

Other studies provide information for planning public surveys. Hays and colleagues' study of 219 well elders in a U.S. retirement community found they were willing to talk about place of death, and most had a clear preference (their retirement community) for place of death and dying. 19 Brazil and colleagues' Canadian study of 216 bereaved family caregivers revealed 77% had a preferred place of death (two thirds preferred the home), and they reported 68% of their deceased family members also had a preferred place of death.<sup>20</sup> A Netherlands survey of the general public revealed their conception of a good death often required that a decision be made by the person and/or family members on the place of death and dying.<sup>21</sup> Another study involving 1035 U.S. psychology students found they were willing and able to talk about death place, with Caucasian Americans more positive about home deaths than African Americans.<sup>22</sup> Additional studies involving nonpopulation-based samples have identified many additional place influences, including the length of the dying process, and pain or other symptoms. 23,24

## Objective

A population-based survey was conducted to examine public preferences for place of last days of life and answer three questions:

- 1. What preferences for the place of last days of life exist among the general public?
- 2. Are preferences related to sociodemographic or other background characteristics?
- 3. Are preferences associated with previous experiences of having had close friends/family members die, having cared for a dying person, having developed a personal directive, and/or having expressed support for legalized death hastening?

## Design

For a representative population-based sample, the University of Alberta's Population Research Laboratory (PRL) was commissioned to include questions in their annual health care telephone survey of adults in Alberta, a province of

western Canada with 3.6 million citizens. A University of Alberta Research Ethics Board provided ethics approval.

A two-stage sampling procedure was used: (1) a random selection of households stratified by geographic area, a third each in metropolitan Edmonton, metropolitan Calgary, and the remainder of the province, using a random-digit dialing method; and (2) selection of a respondent aged 18+ within each selected household, stratified by gender, 50% males and 50% females. The survey aimed for a total sample size of 1200 households. The random-digit dialing approach was used to ensure that respondents had an equal chance of being contacted whether or not their household was listed in a telephone directory.

Participation was voluntary, and respondents were told the survey would take 30 to 45 minutes (40 minute mean). The questionnaire was pretested with 20 households. The survey questions and possible answers (which were supplied if the participant did not answer immediately or asked for the possible answers before responding) were:

- 1. Where would you choose to spend your last days of life? (hospital; nursing home; hospice or another palliative care facility; own home; another person's home, such as a family member or friend; another place such as ...; don't know/not sure/do not want to answer this question)
- Have you ever had a good friend or close family member pass away? (yes; no; don't know/not sure/do not want to answer this question)
- 3. Have you ever looked after or given care to someone who was dying, such as through organizing the person's care, driving him or her to appointments or treatments, feeding, or bathing? (yes; no; don't know/ not sure/do not want to answer)
- 4. Have you ever been involved in a decision to stop or not start life-supporting treatment? This could be your treatment or another person's treatment? (yes; no; don't know/not sure/do not want to answer this question)
- 5. Do you have a living will or personal directive? In Alberta this is a signed, witnessed, and dated paper telling people what you want done if you are ill and not able to talk. (yes, I have one now; no, but I am thinking about it or planning one; no, I do not want or need one; don't know/not sure/do not want to answer this question)
- 6. Should dying adults be able to request and get help from others to end their life early? In other words, this is a request for assisted suicide. (yes, every competent adult should have this right; yes, but it should be allowed in only certain cases or situations; no; don't know/not sure/do not want to answer this question)

The survey was administered through a computer-assisted telephone interviewing (CATI) system, reducing the risk for potential field editing. The interviews were conducted May through July 2010. Substitutions were made when individuals could not be reached after 10 call-backs (at different times during the day and evening, and both on weekdays and weekends); if English language issues were evident; if the person did not meet the criteria for interviewing; or if the person declined to participate. Regardless, data were secured

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Table 1a. Sociodemographic Background and the Preferred Place To Spend the Last Days of Life of the General Population of the Province of Alberta

	Total	Ноте	Hospice/palliative facility	Nursing home n (%) <sup>1</sup>	Hospital	Don't know/not sure	p-value <sup>2</sup>
All	1114	789 (70.8)	164 (14.7)	19 (1.7)	78 (7.0)	64 (5.7)	
Gender							0.013
Male	545 (48.9)	410 (75.2)	67 (12.3)	11 (2.0)	33 (6.1)	24 (4.4)	0.0-0
Female	569 (51.1)		97 (17.0)	8 (1.4)	45 (7.9)	40 (7.0)	
Age							< 0.001
18–24	55 (5.1)	50 (90.9)	0 (0)	0 (0)	1 (1.8)	4 (7.3)	
25–34	127 (11.7)	98 (77.2)	10 (7.9)	2 (1.6)	9 (7.1)	8 (6.3)	
35–44	191 (17.7)	153 (80.1)	17 (8.9)	0 (0)	12 (6.3)	9 (4.7)	
45–54	250 (23.1)	175 (70.0)	41 (16.4)	4 (1.6)	17 (6.8)	13 (5.2)	
55–64	244 (22.6)	150 (61.5)	57 (23.4)	6 (2.5)	16 (6.6)	15 (6.1)	
65+	214 (19.8)	138 (64.5)	37 (17.3)	7 (3.3)	20 (9.3)	12 (5.6)	
Ethnic or cultural group	` ,	` /	, ,	,	,	` '	0.108
North American Aboriginal/Metis	23 (2.1)	15 (65.2)	3 (13.0)	0 (0.0)	4 (17.4)	1 (1.7)	
North American/ European/ Australian, New Zealander	976 (90.4)		154 (15.8)	15 (1.5)	67 (6.9)	53 (5.4)	
Asian	67 (6.2)	52 (77.6)	3 (4.5)	3 (4.5)	3 (4.5)	6 (9.0)	
Other	14 (1.3)	12 (85.7)	2 (14.3)	0 (0.0)	0 (0.0)	0 (0.0)	
Religiosity	( )	(,	(*****)	()	- ()	- ()	0.105
Religious	471 (50.8)	336 (71.3)	77 (16.3)	10 (2.1)	26 (5.5)	22 (4.7)	
Not religious	456 (49.2)		52 (11.4)	8 (1.8)	30 (6.6)	34 (7.5)	
Level of education	` ,	` /	, ,	,	,	` '	0.030
Less than high school	91 (8.2)	59 (64.8)	11 (12.1)	3 (3.3)	12 (13.2)	6 (6.6)	
High school complete	215 (19.4)		21 (9.8)	4 (1.9)	20 (9.3)	11 (5.1)	
Postsecondary	802 (72.4)		131 (16.3)	12 (1.5)	46 (5.7)	46 (5.7)	
Household income	, ,	, ,	, ,	,	, ,	. ,	0.940
Quartile 1	243 (29.1)	168 (69.1)	39 (16.0)	6 (2.5)	18 (7.4)	12 (4.9)	
Quartile 2	334 (40.0	237 (71.0)	57 (17.1)	8 (2.4)	16 (4.8)	16 (4.8)	
Quartile 3	62 (7.4)	45 (72.6)	10 (16.1)	0 (0.0)	3 (4.8)	4 (6.5)	
Quartile 4	195 (23.4)	143 (73.3)	27 (13.8)	2 (1.0)	13 (6.7)	10 (5.1)	

<sup>&</sup>lt;sup>1</sup>Percentages represent row percentages, except in the column Total, where they represent column percentages.

<sup>2</sup>Fisher's exact test.

from the expected representative sample, with almost all persons answering every question. Ten percent of the interviewees were randomly selected and resurveyed by PRL supervisors for interviewing validation.

Data were analyzed using SPSS version 19.0 (SPSS Inc., Chicago, IL), with unadjusted associations between reported EOL experiences and viewpoints of respondents with sociodemographic and other background characteristics also considered relative to preference for place of last days of life, using contingency tables and Fisher's exact tests. The sociodemographic and background variables were household composition, age, gender, marital status, highest level of education, household income, religion, and ethnicity. Adjusted associations were then examined using a main-effects multinomial logistic regression analysis, including all covariates for which the unadjusted association with the preferred place of final days was significant at the 20% level or less. The dependent variable in the regression model was the preferred place of last days, consisting of four categories: home (reference category), hospice or palliative care facility, nursing home, and hospital. A stated preference to spend the last days of life at another person's home was considered equal to a preference for home. A common-law relationship or live-in partner was considered equal to being married.

#### Results

The overall response rate was 21.4% (N=1203). As shown in Tables 1a, 1b, and 2, 70.8% stated a home preference, while 14.7% preferred a hospice/palliative care facility, 7.0% a hospital, 1.7% a nursing home, and 5.7% declined to answer or did not know/were unsure. The home was more often preferred by men, younger people, those with only high school completion, those not widowed, and those not previously involved in a no-treatment or withdrawal of treatment decision. A hospice/palliative care facility was more often preferred by women, older people, those with postsecondary education, widowed persons, and those with previous involvement in a no-treatment or treatment withdrawal decision. Hospitals were preferred by the oldest people, people with education below high school completion, and widowed persons. Ethnic/cultural group, religiosity, household income, number of people in the household, urbanization level, and all other variables were not significantly related to place preference.

Further analysis revealed marital status was the only place predictor (see Table 3). People who were widowed were more likely than married persons to prefer a hospital or hospice/ palliative care facility rather than home. After adjusting for PUBLIC EOL PREFERENCES 505

Table 1b. Sociodemographic Background and the Preferred Place To Spend the Last Days of Life of the General Population of the Province of Alberta

	Total	Ноте	Hospice/palliative facility	Nursing home n (%) <sup>1</sup>	Hospital	Don't know/ not sure	p-value <sup>2</sup>
Marital status							0.005
Never married (single)	142 (12.8)	110 (77.5)	13 (9.2)	1 (0.7)	9 (6.3)	9 (6.3)	
Married/ common law relationship/ live-in partner	808 (72.8)	580 (71.8)	118 (14.6)	14 (1.7)	54 (6.7)	42 (5.2)	
Divorced/ separated	88 (7.9)	63 (71.6)	13 (14.8)	2 (2.3)	4 (4.5)	6 (6.8)	
Widowed	72 (6.5)	34 (47.2)	20 (27.8)	2 (2.8)	11 (15.3)	5 (6.9)	
Adults in household	. ,	, ,	. ,	, ,		. ,	0.370
One	180 (16.2)	117 (65.0)	31 (17.2)	4 (2.2)	16 (8.9)	12 (6.7)	
Two or more	933 (83.8)	672 (72.0)	133 (14.3)	15 (1.6)	62 (6.6)	51 (5.5)	
Children (<18) in household							0.121
None	738 (66.4)	507 (68.7)	120 (16.3)	13 (1.8)	58 (7.9)	40 (5.4)	
One or more	374 (33.6)	281 (75.1)	44 (11.8)	6 (1.6)	20 (5.3)	23 (6.1)	
Urbanization	, ,	, ,	, ,	, ,	, ,	` '	0.406
City	707 (63.3)	497 (70.3)	111 (15.7)	13 (1.8)	43 (6.1)	43 (6.1)	
Town	192 (17.3)	137 (71.4)	26 (13.5)	3 (1.6)	15 (7.8)	11 (5.7)	
Village	30 (2.7)	16 (53.3)	6 (20.0)	1 (3.3)	5 (16.7)	2 (6.7)	
Rural area	183 (16.5)	137 (74.9)	21 (11.5)	2 (1.1)	15 (8.2)	8 (4.4)	

<sup>&</sup>lt;sup>1</sup>Percentages represent row percentages, except in the column Total, where they represent column percentages.

marital status, none of the studied life experiences or personal viewpoints were associated with any place. The logistic regression analysis (with model fitting information: Nagelkerke  $R^2$ =0.086) revealed people who were widowed were more likely than married persons to prefer a hospice/palliative care facility (adjusted OR=3.09, 95% CI=1.44–6.63) and more

likely to prefer a hospital (adjusted OR=4.72, 95% CI=1.74–12.80) over home. The odds ratio was adjusted for gender, age, ethnic/cultural background, religiosity, educational level, marital status, number of children in the household, having been involved in the care of a dying person, and involvement in a no-treatment decision.

Table 2. Experiences With End-of-Life Care and the Preferred Place To Spend the Last Days of Life of the General Population of the Province of Alberta

	Total	Ноте	Hospice/palliative facility	Nursing home N (%) <sup>1</sup>	Hospital	Don't know/ not sure	p-value <sup>2</sup>
Close friend or family							0.546
member pass away?							
Yes	1062 (95.5)	750 (70.6)	160 (15.1)	18 (1.7)	75 (7.1)	59 (5.6)	
No	50 (4.5)	38 (76.0)	4 (8.0)	1 (2.0)	3 (6.0)	4 (8.0)	
Cared for someone who was dying?							0.131
Yes	573 (51.5)	387 (67.5)	96 (16.8)	12 (2.1)	43 (7.5)	35 (6.1)	
No	540 (48.5)	402 (74.4)	68 (12.6)	7 (1.3)	35 (6.5)	28 (5.2)	
Involved in decision to stop or not							0.025
start life-supporting treatment?							
Yes	308 (27.8)	199 (64.6)	61 (19.8)	4 (1.3)	24 (7.8)	20 (6.5)	
No	801 (72.2)	588 (73.4)	103 (12.9)	15 (1.9)	53 (6.6)	42 (5.2)	
Have a living will or personal directive?	, ,	, ,	, ,	, ,	, ,	, ,	0.280
Yes, I have one now	484 (44.1)	340 (70.2)	75 (15.5)	9 (1.9)	36 (7.4)	24 (5.0)	
No, but I am thinking about or planning one	' '	324 (70.1)	76 (16.5)	6 (1.3)	31 (6.7)	25 (5.4)	
No, I do not want or need one	152 (13.8)	114 (75.0)	12 (7.9)	3 (2.0)	11 (7.2)	12 (7.9)	0 F12
Attitude on assisted suicide	277 (2( 0)	2(0 ((0 0)	F( (140)	7 (1.0)	20 (0.0)	24 (6.4)	0.513
Yes, every competent adult should have this right	, ,	260 (69.0)	56 (14.9)	7 (1.9)	30 (8.0)	24 (6.4)	
Yes, but it should only be allowed in certain cases or situations	428 (40.8)	314 (73.4)	67 (15.7)	6 (1.4)	23 (5.4)	18 (4.2)	
No	243 (23.2)	165 (67.9)	36 (14.8)	5 (2.1)	20 (8.2)	17 (7.0)	

<sup>&</sup>lt;sup>1</sup>Percentages represent row percentages, except in the column Total, where they represent column percentages.

<sup>&</sup>lt;sup>2</sup>Fisher's exact test.

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Table 3. Determinants of the Preferred Place To Spend the Last Days of Life of the General Population of the Province of Alberta (N=1114)

	Preferred place to spend the last days of life				
	Hospice/palliative care facility versus home	Nursing home versus home OR (CI 95%)	Hospital versus home		
Sex (versus female) Male	0.67 (0.44–1.01)	1.59 (0.57–4.44)	0.97 (0.53–1.79)		
Age (versus 65+) <65 y	1.28 (0.73–2.25)	0.60 (0.18–2.03)	1.14 (0.50–2.60)		
Ethnic or cultural group (versus other) North American/European/ Australian/New Zealander	1.71 (0.78–3.76)	0.57 (0.15–2.18)	0.85 (0.34–2.15)		
Religiosity (versus not religious) Religious	1.35 (0.90–2.03)	0.97 (0.36–2.64)	0.77 (0.42–1.41)		
Level of education (versus postsecondary) Less than high school High school complete	0.58 (0.24–1.39) 0.58 (0.34–1.01)	1.29 (0.26–6.49) 1.28 (0.39–4.17)	1.57 (0.58–4.27) 1.08 (0.53–2.19)		
Marital status (versus married) Never married Divorced/separated Widowed	0.63 (0.31–1.29) 0.80 (0.37–1.72) 3.09 (1.44–6.63)	0.39 (0.05–3.20) 0.72 (0.09–5.82) 2.21 (0.39–12.54)	1.50 (0.66–3.41) 0.85 (0.24–2.92) 4.72 (1.74–12.80)		
Children in household (versus one or more) None	1.58 (0.98–2.55)	0.98 (0.31–3.15)	1.31 (0.64–2.69)		
Cared for someone who was dying? (versus no) Yes	0.98 (0.63–1.50)	2.17 (0.76–6.18)	1.40 (0.75–2.65)		
Involved in decision to stop or not start life-supporting treatment? (versus no Yes	1.30 (0.83–20.5)	0.61 (0.18–2.00)	1.17 (0.60–2.27)		

### Limitations

Before discussing the findings of this study, it is important to highlight telephone survey limitations, including selection bias. Using a random-digit dialing approach for this telephone survey reduced the risk of selection bias; unlisted, mobile, and landline numbers were equally likely to be included in the sampling frame. Potential selection bias because some people have no telephone is likely to be small, since the proportion of households without any telephone services is very low in Canada. However, despite all efforts made to approach randomization of the obtained sample, selection bias cannot be excluded. Some people may have more than one telephone number, some phone numbers are not linked to persons, and the households linked to a phone number can strongly vary in size. Potential nonresponse bias cannot be ruled out, although up to 10 call-back attempts were made in cases of nonresponse of a potentially eligible respondent, and interviews were spread over different parts of the day on both weekdays and weekend days. The quality of the collected data was assured by the pretesting of the questionnaire, the use of the CATI system, and the resurveying of 10% of the respondents for interviewing validation. Another limitation undermining efforts to ensure an exemplary telephone survey is conducted and data were carefully collected and correctly analyzed is that same telephone polls have raised considerable suspicion as to their value and their findings.

### **Discussion**

This study revealed that the majority (70.8%) of surveyed Albertans preferred to spend their last days at home, as compared to a hospice/palliative care facility (14.7%), hospital (7%), or nursing home (1.7%). Only 5.7% had no preference or were unwilling or unable to indicate one. These findings show most surveyed residents of Alberta, the province with the youngest median age and smallest proportion of citizens over 65 were not only willing to answer a question about their preferred place of death but also had a preference. These findings suggest death and dying understandings that shape place preferences are gained through a wide range of everyday events or processes. Younger surveyed adults had place preference, which could be based on childhood influences.

The home preference finding was striking, as hospitals are readily available as a consequence of Canada's universal, publicly funded health care system. Hospitals, as well as nursing homes and hospices/palliative care facilities, are sites where health care professionals work and technologies are readily available to prevent or address unpleasant symptoms. Furthermore, some studies have indicated death anxiety is common, <sup>26</sup> and that death anxiety can reduce the willingness of people to think about and plan for their own death and dying. <sup>27</sup> It is possible that the public as a whole, or at least the persons surveyed in Alberta, are more aware of and

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comfortable with the concepts of death and dying now, and are more open to talking about and planning for this eventuality. An earlier study also revealed dying people have clear and articulate views about dying.<sup>28</sup>

Although Fukui and colleagues' study showing influences on place preference<sup>18</sup> suggests that experiences related to death and dying, EOL preparations, and personal viewpoints on death hastening would impact place preferences, widowhood emerged in the current study as the only predictor. Widows were more likely to state a preference for a hospital or hospice/palliative care facility. Widowhood could simply limit place options, as many studies have established that the spouse is the primary caregiver for ill and dying persons.<sup>5,11</sup> People who have experienced the death of their spouse have gained insights into the practical, emotional, and other difficulties with death and dying. Although the care needs of dying people vary and they may need help for only a short time, 29-31 it is likely that widowed people have learned that dying persons need assistance with many matters, including first instrumental and then basic activities of daily living. 30,32 Given limitations in publicly funded home care, 5,7,8 home-based dying may be an impossible choice for widowed persons. Clearly, more research on EOL care needs and knowledge dissemination are needed to help the public plan ahead for the end of life, and help more people achieve their preferred EOL place.

Another finding of significance is that widowed persons rarely chose nursing homes, but instead identified hospitals and hospice/palliative care facilities as preferred places. The hospice/palliative facility choice demonstrates public awareness of these specialized centers. This suggests a major social learning achievement, as free-standing hospices are not yet common across Canada and palliative care units are typically only found in larger hospitals.

This disregard of nursing homes by widowed persons helps explain why an "aging in place" strategy for population aging is common across Canada, 33 and why nursing home bed numbers have been stagnant despite population aging. 4 Although it is understandable that no one would wish to be debilitated to the point of needing nursing home care, research should determine how nursing homes could become a preferred EOL place. Nursing homes have already emerged in some countries as places where high-quality EOL care is an aim. Achieving this aim is important, as nursing homes in many countries are already a common place of death. Nursing home deaths are likely to increase with population aging and with more people reaching very old ages. 34

Despite the need for qualitative and other research to establish why widowhood is a major place predictor and why most people chose the home over other places for their final days, the widespread home preference indicates public health interventions are needed to promote good home deaths. As palliative care is not yet fully integrated into the public health agenda, it is an area with great potential.

Research is also needed to address the additional challenges posed by advanced aging, as more people are living to be very old. Many older persons outlive spouses, and as home-based dying typically requires one or more family member caregiver to be present and capable of providing care, issues associated with widowhood and living alone are barriers to home deaths. In addition, some older couples have no children, while others have children who are not physically

or emotionally able to provide EOL care at home. Geographic proximity to informal caregivers is also essential, a factor explaining why some surveyed Albertans chose another home instead of their own.

Research is needed to better understand which if any personal experiences, viewpoints, or EOL preparations, and which (predominant or minority) social values such as autonomy impact not only place preferences but EOL preparations and location of death. An increasing death rate based on the aging population suggests that care provided at home to dying friends and family members needs to be better documented. This information will inform how the options for informal care and care outcomes influence place planning and future actions or outcomes. This research is overdue, as half of those surveyed consider they have already provided EOL care in one form or another. Many have been involved in decisions to stop or not start life-supporting treatment. Many also have developed a living will/personal directive in preparation for the end of life, and developed a viewpoint on legalized assisted suicide.

### Conclusion

This population-based survey provides evidence for consideration across and outside of Canada, notably that most adults prefer to be at home in their final days of life. Although past death and dying experiences and death-hastening viewpoints were expected to influence place preferences, widow-hood emerged as the only place predictor. Marital status should not be considered as a simple decision factor, however. Home-based EOL care may not be possible for them, as they will have learned that assistance from others is usually needed when dying. For this reason and others such as severe or prolonged illnesses, <sup>35</sup> it is important to realize that preferences are heavily impacted by personal and environmental circumstances. The challenge now will be to determine ways and means to ensure more people can stay at home and are not driven by a lack of EOL care options into another place.

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## **Author Disclosure Statement**

There are no conflicts of interest to declare.

## References

- Houttekier D, Cohen J, Surkyn J, Deliens L: Study of recent and future trends in place of death in Belgium using death certificate data: A shift from hospitals to care homes. BMC Public Health 2001;11:228.
- 2. Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP: Preference for place of care and place of death in palliative care: Are these different questions? Palliat Med 2008; 22:787–795.

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 Grande GE, McKerral A, Addington-Hall JM, Todd CJ: Place of death and use of health services in the last year of life. J Palliat Care 2003;19:263–270.

- Scitovsky AA: "The high cost of dying" revisited. Milbank Q 1994;72:561–591.
- Stajduhar KI, Martin WL, Barwich D, Fyles G: Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. Cancer Nurs 2008;31:77–85.
- Zelcer S, Cataudella D, Cairney AE, Bannister SL: Palliative care of children with brain tumors: A parental perspective. Arch Pediatr Adolesc Med 2010;164:225–230.
- Visser G, Klinkenberg M, Broese van Groenou MI, Willems DL, Knipscheer CP, Deeg DJ: The end of life: Informal care for dying older people and its relationship to place of death. Palliat Med 2004;18:468–477.
- 8. Wilson DM, Birch S, Cohen J, MacLeod R, Mohankumar D, Williams A: Home care developments in the Canadian province of Alberta with regionalization. Glob J Health Sci 2011;3:3–8.
- 9. Wilson DM, Cohen J, Birch S, MacLeod R, Mohankumar D, Armstrong P, Froggatt K, Francke A, Low G, McCormack B, Hollis V: "No one dies of old age:" Implications for research, practice, and policy. J Palliat Care 2011;27:148–156.
- Flory J, Yinong YX, Gurol I, Levinsky N, Ash A, Emanuel E: Place of death: U.S. trends since 1980. Health Aff (Millwood) 2004;23:194–200.
- 11. Gomes B, Calanzani N, Higginson IJ: Reversal of the British trends in place of death: Time series analysis 2004–2010. Pall Med 2012;26:102–107.
- 12. British Columbia Ministry of Health Services: Discussion paper on a provincial strategy for end-of-life care in British Columbia. 2002. www.health.gov.bc.ca/library/publications/year/2002/elcpaper.pdf. (Last accessed September 25, 2012.)
- Esteve A, Jimenez C, Perez R, Gomez J: Factors related to withholding life-sustaining treatment in hospitalized elders. J Nutr Health Aging 2009;13:644–650.
- 14. McGeehan R: Verification of expected death. Nurs Stand 2007;22:35–36.
- 15. Penrod J, Hupcey JE, Baney BL, Loeb SJ: End-of-life caregiving trajectories. Clin Nurs Res 2011;20:7–24.
- Williams BA, Lindquist K, Moody-Ayers SY, Walter LC, Covinsky KE: Functional impairment, race, and family expectations of death. J Am Geriatr Soc 2006;54:1682–1687.
- 17. Foreman LM, Hunt RW, Luke CG, Roder DM: Factors predictive of preferred place of death in the general population of South Australia. Palliat Med 2006;20:447–453.
- 18. Fukui S, Yoshiuchi K, Fujita J, Sawai M, Watanabe M: Japanese people's preference for place of end-of-life care and death: A population-based nationwide survey. J Pain Symptom Manag 2011;42(6):882–892.
- 19. Hays JC, Galanos AN, Palmer TA, McQuoid DR, Flint EP: Preference for place of death in a continuing care retirement community. Gerontologist 2001;41:123–128.
- Brazil K, Howell D, Bedard M, Krueger P, Keidebracht D: Preferences for place of care and place of death among information caregivers of the terminally ill. Palliat Med 2005;19:492–499.

21. Rietjens JAC, Van der Heide A, Onwuteaka-Philipsen BD, Van der Maas PJ, Van der Wal G: Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliat Med 2006;20:685–692.

- 22. Webb NM, Tucker D: Young adults' opinions about hospice and home death. J Palliat Med 2009;12:337–342.
- Gomes B, Higginson I: Factors influencing death at home in terminally ill patients with cancer: Systematic review. BMJ 2006;332:515.
- 24. Howell DA, Roman E, Cox H, Smith AG, Patmore R, Garry AC, Howard MR: Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy. BMC Palliat Care 2010;9:9.
- 25. Statistics Canada: *Population Projections: Canada, the Provinces and Territories, 2009–2036.* 2011. www.statcan.gc.ca/daily-quotidien/100526/dq100526b-eng.htm. (Last accessed November 9, 2011.)
- Peck MR: Personal death anxiety and communication about advance directives among oncology social workers. J Soc Work End Life Palliat Care 2009;5:49–60.
- Go RS, Hammes BA, Lee JA, Lee JA: Advance directives among health care professionals at a community based cancer center. Mayo Clin Pro 2007;82:1487–1490.
- 28. Yedidia MJ, MacGregor B: Confronting the prospect of dying: Reports of terminally ill patients. J Pain Symptom Manage 2001;22(4):807–819.
- 29. Murray SA, Kendall M, Boyd K, Sheikh A: Illness trajectories and palliative care. BMJ 2005;330:1007–1011.
- Wilson D: A report of an investigation of end-of-life patient care practices in health care facilities, and the influences for those practices. J Palliat Care 1997;13:34–40.
- Wilson DM: The duration and degree of end-of-life dependency of home care clients and hospital inpatients. Appl Nurs Res 2002;15:81–86.
- Wilson DM: End-of-life care preferences of Canadian senior citizens with caregiving experience. J Adv Nurs 2000;31: 1416–1421.
- 33. Alberta Health: Continuing Care Strategy: Aging in the Right Place. 2008. www.health.alberta.ca/documents/Continuing-Care-Strategy-2008.pdf. (Last accessed February 13, 2013.)
- 34. Wilson DM, Truman C, Thomas R, Fainsinger R, Kovacs-Burns K, Justice C: The rapidly changing location of death in Canada, 1994–2004. Soc Sci Med 2009;68:1752–1758.
- 35. Stajduhar KI, Allan DE, Cohen SR, Heyland DK: Preferences for location of death of seriously ill hospitalized patients: Perspectives from Canadian patients and their family caregivers. Palliat Med 2008;22:85–88.

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