

# Older patient engagement in advance care planning in Canadian primary care practices

## Results of a multisite survey

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### Abstract

**Objective** To assess primary care patients' engagement in advance care planning (ACP) and predictors of engagement.

**Design** Cross-sectional survey using a revised version of a validated questionnaire.

**Setting** Alberta, Ontario, and British Columbia.

**Participants** Convenience sample of 20 family practices that provided a consecutive sample of 810 patients aged 50 years and older.

**Main outcome measures** Engagement in ACP activities, and sociodemographic and health-related predictors of having engaged in ACP activities.

**Results** Patients had a mean age of 66 years (55.6% women). Two-thirds of patients (68.5%; 555) had thought about the kinds of medical treatments they would want or not want if they were sick and in hospital, 52.8% (n=428) had talked with someone about what they would want, 32.0% (n=259) had written down their wishes, 50.4% (n=408) had named someone to be their substitute decision maker, and 23.0% (n=186) had engaged in all 4 key ACP activities. Of those patients who had talked to someone about medical treatments wanted or not, 17.5% (n=75) had talked to their family doctors. Age (adjusted odds ratio per 10-year category of 1.55; 95% CI 1.26 to 1.90;  $P < .001$ ) was significantly associated with having engaged in all ACP activities.

**Conclusion** Many patients have engaged in some ACP activities, but few have discussed ACP with their family physicians. Strategies should be implemented in primary care to reduce the barriers to discussing ACP.

### Editor's key points

- ▶ Advance care planning (ACP) can improve satisfaction with end-of-life care among patients and families and reduce unwanted treatments. There is little information on the extent of ACP in primary care.
- ▶ This survey found that 1 in 4 primary care patients have engaged in all key aspects of ACP; only older age predicted engagement. This suggests that patients might need to be screened for their engagement in specific aspects of ACP and directed to tools that address specific needs.
- ▶ The 52.8% of primary care patients who had talked to someone about ACP nearly always spoke to family members about it, and spoke infrequently to family physicians. Patients could benefit from facilitation of ACP by their primary care providers and strategies should be implemented in this setting to reduce the barriers.

### Points de repère du rédacteur

► Une planification des soins de fin de vie (PSFV) par un patient peut non seulement réduire le nombre de traitements non désirés mais aussi faire en sorte que lui et ses proches soient davantage satisfaits de ces soins. On sait peu de choses sur la place accordée à la PSFV dans le milieu des soins primaires.

► Cette enquête a observé qu'un patient des soins primaires sur quatre avait déjà entrepris une planification de tous les aspects de ses soins de fin de vie; le seul prédicteur d'une telle décision était le fait d'être plus âgé. Cela donne à croire que les patients pourraient profiter d'un dépistage dans ce domaine, et qu'on pourrait leur indiquer des outils pour répondre à des besoins spécifiques.

► Parmi les 52,8 % des patients des soins primaires qui avaient parlé de PSFV à quelqu'un, la très grande majorité en avaient discuté avec des membres de leur famille, alors qu'il était plutôt rare qu'ils en aient discuté avec leur médecin de famille. Les patients auraient davantage à ce que les soignants leur facilitent l'accès à la PSFV, et il faudrait établir des stratégies pour réduire les obstacles éventuels.

# Inciter les patients âgés des cliniques canadiennes de soins primaires à planifier leurs soins de fin de vie

## Résultats d'une enquête multisite

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### Résumé

**Objectif** Vérifier à quel point les patients des soins primaires entreprennent une planification de leurs soins de fin de vie (PSFV) et déterminer les prédicteurs de cette décision.

**Type d'étude** Une enquête transversale à l'aide d'une version révisée d'un questionnaire validé.

**Contexte** L'Alberta, l'Ontario et la Colombie-Britannique.

**Participants** Un échantillon de commodité de 20 pratiques de médecine familiale qui ont permis d'obtenir un échantillon de 810 patients âgés d'au moins 50 ans.

**Principaux paramètres à l'étude** Le fait de s'impliquer dans la PSFV, et les prédicteurs sociodémographiques et de santé de l'implication dans cette activité.

**Résultats** L'âge moyen des patients était de 66 ans, et 55,6 % étaient des femmes. Les deux-tiers d'entre eux (68,5 %; n = 555) avaient déjà réfléchi au type de soins qu'ils voudraient ou ne voudraient pas recevoir en cas d'hospitalisation pour une maladie; 52,8 % (n = 428) en avaient discuté avec quelqu'un; 32,0 % (n = 259) avaient exprimé leurs souhaits par écrit; 50,4 % (n = 408) avaient désigné un mandataire pour prendre ces décisions; et 23,0 % (n = 186) avaient entrepris de s'occuper des 4 principaux aspects de la PSFV. Parmi les patients qui avaient parlé à quelqu'un des traitements qu'ils voulaient ou ne voulaient pas recevoir, seulement 17,5 % (n = 75) en avaient parlé à leur médecin de famille. Il y avait une association significative entre le fait d'avoir entrepris des activités dans tous les domaines de la PSFV et l'âge (rapport de cote ajusté par catégories de 10 ans d'âge de 1,55; IC à 95 % 1,26 à 1,90; P < ,001).

**Conclusion** Beaucoup de patients ont commencé une certaine PSFV, mais peu en ont discuté avec leur médecin de famille. Il serait opportun d'identifier les facteurs qui font obstacle à une telle discussion en milieu de soins primaires.

Most people approaching the end of life express a preference for noninvasive treatment aimed at improving quality of life and symptoms.<sup>1</sup> Yet often the treatments given or ordered are not concordant with people's preferences and are more intensive than desired.<sup>2-4</sup> As people approach the time when decisions about care need to be made during serious illness near the end of life, they might not be able to communicate their preferences.<sup>5,6</sup> When patients have engaged in previous advance care planning (ACP) whereby they have expressed their values and wishes regarding health care to substitute decision makers, end-of-life experiences are improved for patients and family members, there are lower rates of depression and other psychological consequences among families, and unwanted escalation of treatments is more likely to be avoided.<sup>6,7</sup>

The concept of ACP has received considerable attention as a strategy to improve communication and decision making around end-of-life health care.<sup>8</sup> It is important to distinguish the process of ACP from the creation of advance directive or living will documents, which often specify treatment decisions out of context. These documents have been found not to be helpful because patients' preferences change, patients are inadequately informed about treatments, and clinicians might not abide by the requests in such documents.<sup>9-11</sup> The purpose of ACP is to prepare people and their substitute decision makers to be ready for future decisions related to the use of various medical treatments near the end of life.<sup>12</sup> A key concept in ACP is consideration of values regarding what is most important in life and wishes about preferred options or health states that would be acceptable. Based on a published framework and quality indicators endorsed by an expert panel on end-of-life communication and decision making in Canada, the definition of *advance care planning* includes reflection, deliberation, and determination of a person's values and preferences for treatments at the end of life; communication among an individual, his or her loved ones, future substitute decision makers, and health care providers about these values and preferences; and identification of a substitute decision maker. Advance care planning might result in a written expression of preferences, although verbal expressions are also useful.<sup>13</sup>

A barrier to discussions about decision making for end-of-life treatments between health care providers and seriously ill older adults and their families in hospital settings is the lack of preparation, which previous ACP engagement could address.<sup>14</sup> Surveys of health care providers and patients in primary care have revealed the perceptions that ACP engagement should not be left until very advanced age or illness, and that discussions should be initiated by health care providers.<sup>15,16</sup> Primary care is ideally suited to facilitating ACP, in part because of the nature of the relationships between patients and providers.<sup>17,18</sup> Family physicians are guided

by a patient-centred approach,<sup>19</sup> exploring the patient's context, engaging patients and families as active participants in their care, and serving as advocates.<sup>20</sup> The trusting, longitudinal relationship between patients and providers in primary care can facilitate ACP through education, explaining prognosis, and assisting with deliberation around values clarification.

Previous studies of engagement in ACP in primary care have focused on measuring the completion of advance directive documents or "do-not-resuscitate" preferences.<sup>16,21</sup> There is little information about the frequency of engagement in various aspects of ACP as defined above, especially around elements that would be amenable to intervention in primary care, such as communication about values and preferences, and preparation of substitute decision makers. An understanding of engagement in all aspects of ACP is important for future quality improvement initiatives.

The objective of this study was to evaluate the extent to which patients aged 50 years and older in primary care have engaged in key ACP activities and predictors of having completed all aspects of ACP.

## — Methods —

### Setting and design

We conducted a cross-sectional study in primary care practices between October 2014 and March 2015. The study was conducted in a convenience sample of 20 family physicians' practices: 12 practices in Ontario, 6 in Alberta, and 2 in British Columbia. Included practices had a defined patient population (versus episodic walk-in clinics) and provided general family medicine services (as opposed to specialty care such as psychotherapy or sports medicine). A variety of practice types were intentionally recruited to best reflect practice styles across Canada including academic and non-academic practices, groups with and without allied health teams, and solo practitioners.

This study was approved by the research ethics boards of each participating academic institution.

### Participants

Staff members or clinicians were asked to invite consecutive eligible patients to speak to the research assistant. Eligible patients were 50 years of age and older, could read and speak or understand English, and did not have cognitive impairment that would limit participation. The research assistant explained the study and obtained informed consent.

The age of 50 years was chosen because public awareness campaigns emphasize ACP for all adults as a way of normalizing the discussions,<sup>22</sup> early ACP has been advocated in primary care,<sup>15</sup> and 50 is the age at which attention turns to chronic disease and some cancer screening in primary care,<sup>23</sup> providing an opportunity for healthy older adults to be introduced to ACP.

## Questionnaire

We adapted a questionnaire that was previously developed and validated for use in hospitalized patients.<sup>24</sup> The hospital version has face and content validity, good ratings of clarity, and low psychological burden. We modified this questionnaire for use in primary care and piloted it with 25 patients in primary care to assess its clarity, sensibility, and acceptability. Revisions were made to improve clarity.

The questionnaire asked whether patients had heard of ACP previously (a definition was provided) and whether they had engaged in 4 key ACP activities including having thought about the kinds of medical treatments they would want or not want if they were to get very sick and be in hospital; having talked to anyone about their wishes (and to whom); having written down their wishes; and having formally nominated a substitute decision maker.<sup>8</sup> Questions also included sociodemographic characteristics and a brief frailty index.<sup>25</sup>

Within 7 days of patients completing the questionnaire, research assistants reviewed the charts of patients to record comorbidities (to calculate the Charlson Comorbidity Index score).<sup>26</sup>

## Statistical analysis

A sample size of 30 to 50 patients was targeted in each family practice to allow a reasonable number to provide a feedback report of results to the practice.

Characteristics of patients were described as counts and percentages for categorical variables and as means with SDs and ranges for continuous variables. The components of ACP were reported as percentages of patients. We conducted logistic regression to determine sociodemographic and health-related predictors independently associated with having completed all 4 ACP activities. We chose to model completion of all 4 ACP activities because patients who could benefit from tools and interventions in primary care include those with a gap in completion of any aspect of ACP. Independent variables in the multivariate logistic model were age, sex, education, marital status, living alone or not, rural versus urban residence, importance of religion or spirituality, language spoken at home, ethnicity, self-reported health, self-reported quality of life, and self-reported frailty index rating, and Charlson Comorbidity Index score. The logistic model was stratified by family practice to account for a potential clustering effect. Analyses were conducted using SAS, version 9.4.

## Results

**Table 1** shows the characteristics of the participating practices.<sup>27,28</sup> Most of the family practices were group practices, with most employing allied health professionals, while only 3 were academic teaching clinics.

The survey was completed by 810 patients (92.2% completion rate among patients approached by practice

staff who agreed to talk to the research assistant). The number of patients recruited per family practice ranged from 23 to 140 (in 1 practice with multiple physicians, approximately 20 patients per physician were recruited). The mean age of patients was 66 years (range 50 to 95 years) and 55.6% were women (450 of 809) (**Table 2**). Most patients identified themselves as white or Caucasian (88.0%; 713 of 810). Most patients (88.3%; 712 of 806) reported being very fit, well, or managing well on the frailty scale.

More than half of patients (58.0%; 470 of 810) were unaware of the term *advance care planning*. Two-thirds of patients (68.5%; 555 of 810) had thought about the kinds of medical treatments they would want or not want if they were to get sick and be in hospital, 52.8% (428 of 810) had talked with someone about treatments wanted or not wanted, 32.0% (259 of 810) had written down their wishes, 50.4% (408 of 810) had named someone in writing to be their substitute decision maker, and 23.0% (186 of 810) reported having engaged in all 4 ACP activities (**Table 3**). Of those patients who had talked to someone about medical treatments, 92.1% (394 of 428) reported they had talked to family members, 23.4% (100 of 428) to a lawyer, and 17.5% (75 of 428) to a family doctor. More patients reported being quite comfortable or very comfortable talking with a family doctor (79.1%; 640 of 809) than talking with family members (68.7%; 556 of 809) about medical treatment options concerning the end of life.

Of the sociodemographic and health status characteristics examined for association with completion of all aspects of ACP, only age was statistically significant in multivariate analysis (adjusted odds ratio per 10-year age increment of 1.55; 95% CI 1.26 to 1.90;  $P < .001$ ) (**Table 4**).

## Discussion

We surveyed 810 patients aged 50 and older from 20 primary care clinics in 3 Canadian provinces and found that most patients had engaged in some ACP tasks, but few had completed all 4 activities. Few patients had talked about the medical treatments they would want near the end of life with their family physicians.

The results of this study in primary care were similar to those of a 2012 public opinion poll in Canada.<sup>29</sup> Approximately half of participants in both the current study and the poll reported having a substitute decision maker and having had ACP discussions with family or friends. Advance care planning conversations with a health care provider were reported by fewer participants. Advance care planning engagement appears to be much higher in primary care in Canada compared with findings of a mailed survey of general practice patients in the United Kingdom, where 12% of patients had talked to someone about ACP and 13% had prepared an advance directive.<sup>30</sup> In contrast to primary care, the prevalence of engagement in ACP activities among

**Table 1. Characteristics of participating family practices in the 3 provinces and national comparisons**

| CHARACTERISTIC                      | ALBERTA (N 6),<br>N (%) | BRITISH COLUMBIA<br>(N 2), N (%) | ONTARIO (N 12),<br>N (%) | TOTAL (N 20),<br>N (%) | CANADA,* %        |
|-------------------------------------|-------------------------|----------------------------------|--------------------------|------------------------|-------------------|
| Type of practice                    |                         |                                  |                          |                        |                   |
| • Group                             | 6 (100.0)               | 2 (100.0)                        | 9 (75.0)                 | 17 (85.0)              | 81.3 <sup>†</sup> |
| • Solo                              | 0 (0.0)                 | 0 (0.0)                          | 3 (25.0)                 | 3 (15.0)               | 18.7 <sup>†</sup> |
| Teaching clinic                     | 1 (16.7)                | 0 (0.0)                          | 2 (16.7)                 | 3 (15.0)               | NA                |
| Allied health professionals         | 6 (100.0)               | 1 (50.0)                         | 10 (83.3)                | 17 (85.0)              | 19.1              |
| Urban or suburban practice location | 6 (100.0)               | 2 (100.0)                        | 10 (83.3)                | 20 (100.0)             | 67.5              |

NA—not available.  
\*Canada-wide data from the National Physician Survey.<sup>27,28</sup>  
<sup>†</sup>Hospital-based practice data and nonresponses were excluded.

**Table 2. Characteristics of patients from primary care practices: N 810 unless otherwise specified.**

| CHARACTERISTIC                                                                   | VALUE      |
|----------------------------------------------------------------------------------|------------|
| Mean (SD) age, y                                                                 | 66 (10)    |
| Age range, y                                                                     | 50 to 95   |
| Female sex (N = 809), n (%)                                                      | 450 (55.6) |
| Marital status (N = 809), n (%)                                                  |            |
| • Married or in a relationship                                                   | 558 (69.0) |
| • Widowed                                                                        | 100 (12.4) |
| • Divorced or single                                                             | 151 (18.7) |
| Lives alone (N = 809), n (%)                                                     | 179 (22.1) |
| Urban residence (self-defined) (N = 806), n (%)                                  | 718 (89.1) |
| Highest level of education is some or completed postsecondary (N = 808), n (%)   | 500 (61.9) |
| Spirituality or religion is very or extremely important (N = 808), n (%)         | 365 (45.2) |
| Identifies with formal religious group or practice (N = 805), n (%)              |            |
| • Protestant                                                                     | 295 (36.6) |
| • Catholic                                                                       | 194 (24.1) |
| • Other                                                                          | 136 (16.9) |
| • None                                                                           | 180 (22.4) |
| Identifies as Caucasian or white, n (%)                                          | 713 (88.0) |
| Speaks a language other than English or French on a daily basis (N = 807), n (%) | 129 (16.0) |
| Self-reported health (N = 805), n (%)                                            |            |
| • Excellent, very good, or good                                                  | 661 (82.1) |
| • Fair or poor                                                                   | 144 (17.9) |
| Self-reported quality of life (N = 806), n (%)                                   |            |
| • Excellent, very good, or good                                                  | 736 (91.3) |
| • Fair or poor                                                                   | 70 (8.7)   |
| Frailty index (N = 806), n (%)                                                   |            |
| • Very fit, well, or managing well                                               | 712 (88.3) |
| • Vulnerable or frail                                                            | 94 (11.7)  |
| Mean (SD) Charlson Comorbidity Index score                                       | 1 (1)      |
| • Range                                                                          | 0 to 10    |

seriously ill, older hospitalized patients in Canada was higher: 73% had a substitute decision maker and 55% had discussed ACP with a health care provider (30% with a family physician).<sup>31</sup>

We found that of the 52.8% of primary care patients who had talked to someone, it was nearly always to family members, and infrequently to family physicians. Lack of ACP communication between patients and their health care providers has been well documented in both primary care and hospital settings.<sup>16,21,30,31</sup> Previous studies have reported that most patients would welcome a discussion with their family physicians.<sup>16,21</sup>

It is difficult to predict which patients have engaged in all aspects of ACP, as older age and the presence of a serious health condition are not consistent predictors of having completed ACP, and people do not engage in ACP activities sequentially.<sup>32</sup> In our model of factors associated with having completed all 4 aspects of ACP, only increasing age was statistically significantly associated with completion, controlling for all other sociodemographic and health status factors. The finding suggests that patients might need to be screened for their engagement in specific aspects of ACP and directed to tools that address specific needs.

### Strengths and limitations

A strength of this study is that it was conducted across multiple family practices and jurisdictions and the previously validated acute care survey instrument<sup>24</sup> was adapted for primary care and pilot-tested. There were also limitations to our study. Family practices and patients were not randomly selected. We used visit-based patient sampling, which has been shown to overrepresent more frequent attenders who are older and have more health problems compared with the full practice population.<sup>33</sup> Owing to varying work flow styles in the practices and intermittent referral during busy times, we could not be certain that all consecutive patients were referred to the research assistant. If our sample included patients who were more interested in ACP, our study might overestimate ACP engagement in patients attending primary care. An additional



**Table 3. Prevalence of ACP awareness and activities reported by the primary care patients: N 810 unless specified otherwise.**

| QUESTION                                                                                                                                   | N (%)      |
|--------------------------------------------------------------------------------------------------------------------------------------------|------------|
| Have you ever thought about what kinds of medical treatments you would want or not want if you were to get very sick and be in a hospital? | 555 (68.5) |
| Have you talked with anyone about what medical treatments you would want or not want at the end of life? If yes ... (N = 428)              | 428 (52.8) |
| • Family doctor                                                                                                                            | 75 (17.5)  |
| • Nurse                                                                                                                                    | 9 (2.1)    |
| • Social worker                                                                                                                            | 4 (0.9)    |
| • Spiritual care worker                                                                                                                    | 7 (1.6)    |
| • Other doctor                                                                                                                             | 16 (3.7)   |
| • Family members                                                                                                                           | 394 (92.1) |
| • Substitute decision maker                                                                                                                | 21 (4.9)   |
| • Lawyer                                                                                                                                   | 100 (23.4) |
| • Other                                                                                                                                    | 26 (6.1)   |
| Have you written down your wishes about medical treatments you would want or not want in the event you are unable to speak for yourself?   | 259 (32.0) |
| Have you named someone, in writing, to be your substitute decision maker for medical treatment decisions?                                  | 408 (50.4) |
| No. of ACP activities reported (N = 809)                                                                                                   |            |
| • 0                                                                                                                                        | 152 (18.8) |
| • 1                                                                                                                                        | 154 (19.0) |
| • 2                                                                                                                                        | 199 (24.6) |
| • 3                                                                                                                                        | 118 (14.6) |
| • 4                                                                                                                                        | 186 (23.0) |

ACP = advance care planning.

**Table 4. Association between sociodemographic and health status variables and reporting engagement in all 4 advance care planning activities among 810 patients in primary care**

| VARIABLE                                                                      | UNADJUSTED ODDS RATIO (95% CI) | ADJUSTED ODDS RATIO (95% CI) | P VALUE* |
|-------------------------------------------------------------------------------|--------------------------------|------------------------------|----------|
| Age (10-y categories)                                                         | 1.61 (1.35 to 1.92)            | 1.55 (1.26 to 1.90)          | <.001    |
| Sex (female vs male)                                                          | 0.96 (0.68 to 1.36)            | 1.04 (0.71 to 1.52)          | .86      |
| Marital status (married or in a relationship vs other)                        | 0.58 (0.40 to 0.84)            | 0.67 (0.35 to 1.29)          | .23      |
| Lives alone (no vs yes)                                                       | 0.51 (0.34 to 0.75)            | 0.91 (0.45 to 1.83)          | .79      |
| Location of residence (urban vs rural)                                        | 1.50 (0.82 to 2.72)            | 1.32 (0.70 to 2.46)          | .39      |
| Highest education (some or completed postsecondary education vs other)        | 1.00 (0.70 to 1.42)            | 1.26 (0.85 to 1.87)          | .24      |
| Spirituality or religion (very or extremely important vs other)               | 1.16 (0.82 to 1.65)            | 1.06 (0.72 to 1.57)          | .76      |
| Religious group                                                               |                                |                              | .33      |
| • Catholic vs Protestant                                                      | 1.30 (0.79 to 2.13)            | 1.27 (0.78 to 2.09)          |          |
| • None vs Protestant                                                          | 1.01 (0.63 to 1.61)            | 1.11 (0.67 to 1.85)          |          |
| • Other vs Protestant                                                         | 1.03 (0.65 to 1.65)            | 1.64 (0.96 to 2.80)          |          |
| Ethnicity (white or Caucasian vs other)                                       | 1.27 (0.69 to 2.33)            | 1.21 (0.63 to 2.33)          | .57      |
| Speak language on a daily basis other than English or French (yes vs no)      | 0.73 (0.42 to 1.25)            | 0.64 (0.36 to 1.15)          | .14      |
| Self-reported health (excellent, very good, or good vs fair or poor)          | 0.94 (0.66 to 1.33)            | 1.13 (0.72 to 1.78)          | .60      |
| Self-reported quality of life (excellent, very good, or good vs fair or poor) | 0.77 (0.54 to 1.09)            | 0.64 (0.40 to 1.01)          | .06      |
| Frailty index (vulnerable or worse vs other)                                  | 1.48 (0.90 to 2.44)            | 1.48 (0.84 to 2.59)          | .18      |
| Charlson Comorbidity Index score <sup>†</sup>                                 | 1.18 (1.05 to 1.34)            | 1.09 (0.94 to 1.26)          | .24      |

\*P values from the multivariate model.

<sup>†</sup>Continuous variable.

potential limitation to representativeness was that study patients were required to speak and understand English, and only 12% identified themselves as not white or Caucasian, which is not representative of the contemporary Canadian population.<sup>34</sup> Despite these limitations, our findings add important new knowledge about ACP engagement from a sample of patients visiting their primary care providers.

## Conclusion

This study found that 1 in 4 primary care patients have engaged in all key aspects of ACP and that only older age predicted engagement. A minority of primary care patients have discussed ACP with their family physicians. Patients could benefit from facilitation of ACP by their primary care providers and strategies should be implemented in this setting to reduce the barriers.

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## Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

## Competing interests

None declared

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