



Editor's key points

► People who engage in advance care planning (ACP) are more likely to receive health care that is concordant with their goals and wishes at the end of life. Primary care providers might be ideally positioned to introduce and facilitate ACP. This study aimed to identify barriers to and enablers of ACP perceived by physicians and other health professionals in primary care.

► In this survey, family physicians and other primary care providers rated barriers related to patient characteristics and system factors the highest. Lack of time was the greatest barrier for family physicians but it was significantly less of a barrier for allied health professionals ($P < .001$), who struggled more with a lack of knowledge ($P < .001$) and access to physician support.

► The recommendation of having ACP resources for the family practice and for patients was a main theme that emerged as an enabler. There is an opportunity to address physicians' lack of time for discussions and patients' lack of understanding of how treatment decisions are made by better preparing patients for ACP discussions with accurate information and resources.

Barriers to and enablers of advance care planning with patients in primary care

Survey of health care providers

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Abstract

Objective To identify barriers to and enablers of advance care planning (ACP) perceived by physicians and other health professionals in primary care.

Design Cross-sectional, self-administered survey.

Setting Ontario, Alberta, and British Columbia.

Participants Family physicians ($n = 117$) and other health professionals ($n = 64$) in primary care.

Main outcome measures Perceived barriers relating to the clinician, characteristics of patients, and system factors, rated on a 7-point scale from 0 (not at all) to 6 (an extreme amount), and enablers reported using an open-ended question.

Results Between November 2014 and June 2015, questionnaires were returned by 72.2% (117 of 162) of family physicians and 68.8% (64 of 93) of the other health professionals. Physicians rated insufficient time, inability to electronically transfer the advance care plan across care settings, decreased interaction with patients near the end of life owing to transfer of care, and patients' difficulty understanding limitations and complications of treatment options as the highest barriers. Other health professionals additionally identified their own lack of knowledge and difficulty accessing the physician as barriers. Themes identified as enablers included greater public engagement, clinician attitudes, creating capacity for clinicians, integrating ACP into practice, and system and policy supports.

Conclusion In primary care, there are barriers to engaging patients in ACP at the patient, provider, and system levels that could potentially be addressed through the informed development of multifaceted interventions.



Les facteurs qui facilitent la planification préalable des soins chez les patients des soins primaires ou qui y nuisent

Une enquête auprès de prestataires de soins

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Résumé

Objectif Déterminer les facteurs qui facilitent la planification préalable des soins (PPS) selon les médecins de famille et les autres professionnels de la santé qui dispensent des soins primaires, ou qui y nuisent.

Type d'étude Une enquête transversale auto-administrée.

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

Participants Des médecins de famille (n = 117) et d'autres professionnels de la santé (n = 64) prestataires de soins primaires.

Principaux paramètres à l'étude Les obstacles perçus liés au médecin, aux caractéristiques des patients et aux facteurs systémiques, cotés de 0 (pas du tout) à 6 (valeur extrême) sur une échelle de 7 points, et les facteurs de facilitation signalés à l'aide d'une question ouverte.

Résultats Entre novembre 2014 et juin 2015, les questionnaires ont été retournés par 117 médecins de famille sur 162 (72,2%) et par 64 professionnels de la santé sur 93 (68,8%). Pour les obstacles, les médecins ont attribué la plus haute note à un manque de temps, à l'incapacité de gérer l'inscription d'une telle planification des soins futurs dans le dossier électronique durant le traitement d'un patient, à une diminution des rencontres avec le patient en fin de vie à cause d'un transfert des soins, et au fait que les patients ont de la difficulté à comprendre les limitations et les complications de ce choix. Les autres professionnels de la santé ont mentionné comme obstacles leur propre manque de connaissances dans ce domaine et la difficulté à avoir accès à un médecin. Les thèmes considérés comme des facteurs de facilitation comprenaient une plus grande participation du public, l'attitude des cliniciens, un renforcement des compétences des cliniciens, l'intégration de la PPS dans la pratique, et un soutien accru du système et des politiques.

Conclusion Dans les soins primaires, certains facteurs liés aux prestataires de soins, au système de santé et au patient lui-même empêchent les patients de s'engager dans la PPS; on pourrait s'attaquer à ces problèmes par l'élaboration éclairée d'interventions multiples.

Points de repère du rédacteur

► Les personnes qui s'engagent dans la planification préalable des soins (PPS) sont plus susceptibles de recevoir des soins qui correspondent à leurs buts et à leurs souhaits en fin de vie. Les prestataires de soins primaires sont peut-être les mieux placés pour leur suggérer la PPS et la faciliter. Cette étude cherchait à déterminer les facteurs qui facilitent la planification préalable des soins ou qui y nuisent selon les médecins et les autres professionnels de la santé prestataires de soins primaires.

► Dans cette enquête, des médecins de famille et d'autres prestataires de soins primaires ont estimé que les caractéristiques des patients et certains facteurs systémiques étaient les obstacles les plus importants. Pour les médecins de famille, le principal obstacle était le manque de temps, alors que pour les autres professionnels de la santé, qui se disaient être confrontés à un manque de connaissances ($P < .001$) et d'accès au soutien du médecin, ce facteur était significativement moins important ($P < .001$).

► La recommandation de disposer de ressources adéquates pour la clinique et pour les patients était un thème récurrent, perçu comme un facteur de facilitation. Il serait possible de s'attaquer au manque de temps des médecins pour en discuter et au manque de compréhension des patients sur la façon de prendre les décisions en préparant mieux les patients aux discussions sur la PPS, avec de l'information et des ressources adéquates.

Interest has emerged in improving the provision of health care during serious illness or near the end of life; research shows that patients and families wish to be engaged in communication and decision making about treatments with health care professionals.^{1,2} Hospital care near the end of life often involves the use of technology-laden, invasive, life-sustaining treatment,³⁻⁵ yet patients and families often have strong preferences at the end of life for care that is focused on comfort rather than invasive treatments.^{2,5,6} Previous engagement in advance care planning (ACP) is associated with improved patient and family experiences with health care near the end of life, greater concordance between patient wishes and the health care they receive, and fewer unwanted intensive treatments.^{7,8} *Advance care planning* is defined as a communication process wherein people plan for a time when they cannot make decisions for themselves. It includes reflection, deliberation, and determination of a person's values and preferences for treatments at the end of life, identification of a substitute decision maker, and communication among an individual and his or her loved ones, future substitute decision makers, and health care providers about these values and preferences.⁹ It can result in a written expression of wishes.⁹

Family practice is the setting in which longitudinal, relationship-centred care across the life cycle is provided for most Canadians.¹⁰ Discussions about ACP initiated in the primary care setting could ensure that patients and families are better prepared to make in-the-moment decisions they might face elsewhere in the health care system. Further, patients often expect their primary care provider to initiate the discussion.^{11,12} However, health care professionals and patients in primary care infrequently discuss ACP.^{13,14} To increase the quantity and quality of ACP in primary care, interventions guided by knowledge of the specific barriers to and facilitators of ACP in this setting are needed.

A systematic review of studies that examined barriers to and facilitators of ACP for general practitioners provided a description of physician, patient, and health system barriers but did not quantify or rank the prevalence or importance of those barriers.¹⁵ Also, there has been little study of the barriers among nurses or other providers in primary care. We undertook a cross-sectional survey to assess the perceived barriers to and enablers of engaging in ACP with patients from the perspective of family physicians and other health professionals in primary care.

— Methods —

We conducted a self-administered survey of health care professionals in primary care in the provinces of Ontario, Alberta, and British Columbia from November 2014 to June 2015.

Questionnaire administration

An online survey link (FluidSurveys) with a unique identifier was sent to each potential participant by e-mail. The introductory letter stated that the survey was intended for clinicians working in a primary care practice. We recruited primary care clinicians in several ways: some were taking part in our larger study on ACP¹⁶ and some were recruited through relevant organizations, events, or rounds. In addition, family physician professional organizations included the survey invitation in e-mail newsletters during late 2014. For clinicians who indicated an interest, we used an established method for questionnaire distribution to maximize response rates, which included sending an invitation letter with the questionnaire and sending up to 2 reminders, including resending the unique link for nonresponders.^{17,18}

Questionnaire development

We based the questionnaire structure on previously published surveys for physicians and nurses that assessed perceived barriers to and enablers of goals-of-care discussions in the hospital setting.¹⁹ To augment and contextualize the items for primary care, we consulted a systematic review of barriers to and facilitators of ACP in primary care,¹⁵ adding items from this review that were not already represented. We conducted 2 focus groups with family physicians and members of our research team (family physicians [C.B., D.K., A.T.], palliative care physicians [M.S., D.B.], a critical care physician [D.K.H.], and end-of-life care and primary care researchers [M.H., D.E., J.J.Y.]) to further refine items to assure content validity and wording clarity. Using the family physician version of the questionnaire, we then conducted 2 focus groups with primary care nurse practitioners, palliative home care nurses, and a social worker to identify additional items perceived as barriers from a nursing perspective. The questionnaires were reviewed again for content and clarity by the research team.

The physicians were asked to rate the importance of 31 barriers to ACP discussions with the general population of patients aged 50 and older in their practice over the past month; 9 barriers were related to patient or family member factors, 14 were related to clinician factors, and 8 were related to system factors. The nursing and allied health professional version contained 9 barriers related to patient or family member factors, 14 barriers related to clinician factors, 7 barriers related to system factors, and 5 barriers related to the role of physicians. In each version, an open-ended question asked about suggestions to overcome barriers. Demographic and practice characteristics of the respondents were also elicited in both versions.

Analyses

The primary outcome was respondent ratings of the magnitude of each barrier using a 7-point scale from 0 to 6 (not at all, very little, a little, a moderate amount, a

lot, a great deal, an extreme amount). Categorical variables are described as counts. Percentages and continuous variables are described as means and SDs. Pairwise comparisons between professional groups were conducted using a linear mixed-effects model (with site as a random effect) that accounted for dependence between participants within the same practice.

We conducted a qualitative analysis of perceived enablers of ACP from the open-ended survey question: "Reflecting on the most important barriers which you have just rated, in Section 1, what specific suggestions do you have about ways to overcome these barriers and make it easier for you and other healthcare providers in primary care to talk with patients about ACP?" Thematic content analysis was done. Two authors (M.H., D.E.) independently read the comments and created a preliminary coding framework, which was discussed and revised by consensus. All comments were then independently coded by the 2 analysts. Themes and subthemes emerged from the data and framework. The analysts reached consensus through discussion of the final themes and subthemes. The data and framework were reviewed by a family doctor (D.K.) who noted 1 additional subtheme and agreed with the remainder of the analysis.

— Results —

Among physicians, the response rate was 72.2% (117 of 162), with complete data on barriers for 112 respondents. Among other health professionals, the response rate was 68.8% (64 of 93), with complete data on barriers for 58 respondents. Characteristics of respondents are shown in **Table 1**. Most physicians (76.8%; 86 of 112) were practising in interprofessional team models.

Results are presented as the mean rating of barriers related to the clinician, barriers related to patients or families, and barriers related to the practice or system (**Table 2**). For physicians, 4 barriers were rated with a mean score of 3 (a moderate amount) or higher: insufficient time, inability to electronically transfer the patient's advance care plan, decreased interaction with patients owing to transfer of care, and patients' difficulty understanding the limitations and complications of life-sustaining therapies. The least important barriers (mean rating <1) were the perception that it is their job to cure people, the perception that patients should initiate the discussion, the perception that other health care professionals are better positioned, and the perception that discussing ACP would negatively affect the relationship with patients.

Among other health professionals, there were 12 barriers with a mean score of 3 or higher (**Table 2**). Three of the top barriers were the same as for physicians: inability to electronically transfer the patient's advance care plan, decreased interaction with patients owing to transfer of care, and patients' difficulty understanding the limitations

and complications of life-sustaining therapies. Allied health professionals rated a lack of knowledge of ACP significantly higher compared with physicians ($P < .001$) and rated lack of time significantly lower ($P < .001$).

Suggestions of ways to make it easier to talk about ACP with patients in primary care were provided by 85 physicians and 25 allied health professionals. Five main themes emerged: public engagement, health care provider attitudes, creating capacity for primary care providers, integration of ACP into the work flow, and system and policy supports (**Table 3**).

— Discussion —

In this survey of barriers to having ACP discussions, family physicians and other primary care providers rated barriers related to patient characteristics and system factors the highest. Lack of time was the greatest barrier for family physicians but not for allied health professionals. For allied health professionals, lack of knowledge about how to do ACP and insufficient access to physicians to support ACP were among the greatest barriers. The recommendation of having ACP resources for the family practice and for patients was a main theme that emerged as an enabler. There is an opportunity to address physicians' lack of time for discussions and patients' lack of understanding of how treatment decisions are made by better preparing patients with accurate information and resources about ACP so that the time required for discussions could potentially be reduced.

Our findings complement those of a national public opinion poll on ACP, where only a small proportion (10%) of adults reported ever having discussed ACP with a health care provider.¹⁴ A systematic review of barriers to engagement in ACP among general practitioners found that difficulty dealing with vague requests from patients, difficulty defining the right moment, fear of depriving patients of hope, and expectations (if present) that patients should initiate ACP were barriers.¹⁵ We found that these same barriers were not rated highly in terms of importance to the respondents' own practices. In fact, concern about the effect of initiating ACP on relationships with patients and the perception that patients should initiate ACP were among the lowest rated barriers among family physician respondents. Our findings suggest the existence of trusting relationships between providers and patients that can be leveraged to increase engagement in ACP in primary care.

Allied health professionals recommended that having greater clarity around their expected role in ACP would be a facilitator to engaging with patients. Numerous models of interprofessional primary care exist, with many models designed to respond to chronic illness management through team-based care²⁰; therefore, it is important to be able to design interventions for primary

Table 1. Baseline characteristics of survey respondents: A total of 112 primary care physicians and 58 nurses and other health professionals in primary care responded in full to the section on barriers, but 2 physicians and 1 other health professional did not complete the demographic portion of the survey.

| CHARACTERISTICS | ALL | PHYSICIANS | NURSES AND OTHER HEALTH PROFESSIONALS* |
|---|-------------|-------------|--|
| Mean (SD) age, y | 45.4 (12.8) | 47.6 (11.9) | 41.4 (13.5) |
| Female sex, n (%) | 108 (64.7) | 54 (49.1) | 54 (94.7) |
| White ethnicity, n (%) [†] | 125 (77.6) | 85 (79.4) | 40 (74.1) |
| Religious background, n (%) | | | |
| • Catholic, Protestant, Orthodox, or other Christian | 86 (51.5) | 51 (46.4) | 35 (61.4) |
| • Jewish | 10 (6.0) | 8 (7.3) | 2 (3.5) |
| • Other or no religious affiliation | 71 (42.5) | 51 (46.4) | 20 (35.1) |
| Country trained in | | | |
| • Canada | 147 (88.0) | 94 (85.5) | 53 (93.0) |
| • Other | 20 (12.0) | 16 (14.5) | 4 (7.0) |
| Mean (SD) years in practice | 18.0 (13.3) | 19.2 (12.8) | 15.8 (14.2) |
| Self-rated skills in ACP discussions, n (%) | | | |
| • Limited | 34 (20.4) | 7 (6.4) | 27 (47.4) |
| • Fair | 24 (14.4) | 11 (10.0) | 13 (22.8) |
| • Average | 63 (37.7) | 52 (47.3) | 11 (19.3) |
| • Very good | 32 (19.2) | 28 (25.5) | 4 (7.0) |
| • Expert | 14 (8.4) | 12 (10.9) | 2 (3.5) |
| Priority for learning ACP skills, n (%) [‡] | | | |
| • 1 (low priority, not of interest, or already mastered) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| • 2 | 12 (9.1) | 7 (8.2) | 5 (10.6) |
| • 3 | 49 (37.1) | 32 (37.6) | 17 (36.2) |
| • 4 | 70 (53.0) | 46 (54.1) | 24 (51.1) |
| • 5 (high priority, first priority on personal learning agenda) | 1 (0.8) | 0 (0.0) | 1 (2.1) |
| Have undertaken extra training or certification in palliative care, n (%) | 36 (21.6) | 24 (21.8) | 12 (21.1) |
| Employer, n (%) [§] | | | |
| • The physicians in your practice | NA | NA | 10 (18.2) |
| • A primary care group model (eg, primary care network, family health team) | NA | NA | 40 (72.7) |
| • Other | NA | NA | 5 (9.1) |

ACP—advance care planning, NA—not applicable.

*Among the other health professionals, 24 were registered nurses, 10 were nurse practitioners or advanced practice nurses, 6 were registered practical nurses, 7 were social workers, 10 indicated other (eg, psychologist, physician assistant), and 7 did not indicate their profession. Not all provided complete data.

[†]Only 107 physicians and 54 other health professionals answered this question.

[‡]Only 85 physicians and 47 other health professionals answered this question.

[§]Only 55 other health professionals answered this question.

Table 2. Mean importance of barriers to ACP among 112 primary care physicians and 58 nurses and other health professionals in primary care: Items were rated on a 7-point scale from 0 (not at all) to 6 (an extreme amount) and are listed in descending order of magnitude of mean overall rating within each section.

| BARRIERS | ALL, MEAN (SD) | PHYSICIANS, MEAN (SD) | OTHER HEALTH CARE PROFESSIONALS, MEAN (SD) | P VALUE |
|---|----------------------|--------------------------|---|------------|
| Barriers related to own role | | | | |
| • My difficulties with defining the right moment to engage patients in ACP | 2.5 (1.5) | 2.4 (1.4) | 2.8 (1.7) | .32 |
| • My lack of knowledge about the legal status of ACP documents in the province | 2.4 (1.7) | 1.9 (1.4) | 3.4 (1.9) | <.001 |
| • My difficulties in dealing with uncertainty of prognosis for patients with chronic illness | 2.2 (1.4) | 1.9 (1.3) | 2.7 (1.6) | .05 |
| • My lack of knowledge about ACP and its relationship to advance directives and goals-of-care discussions | 2.1 (1.6) | 1.7 (1.3) | 3.1 (1.7) | <.001 |
| • My doubts about the availability or accessibility of ACP documents when they are needed in the future to make medical decisions | 2.0 (1.5) | 2.1 (1.5) | 1.9 (1.5) | .35 |
| • My lack of knowledge about how to elicit values, beliefs, and preferences related to end-of-life care | 1.9 (1.4) | 1.6 (1.1) | 2.7 (1.7) | <.001 |
| • My difficulties in dealing with patients' changing preferences for medical treatments at the end of life | 1.8 (1.3) | 1.6 (1.2) | 2.3 (1.6) | .17 |
| • My having to deal with the emotional effects of ACP conversations with patients | 1.6 (1.4) | 1.4 (1.2) | 2.0 (1.6) | .07 |
| • My belief that other health care professionals are better positioned to initiate ACP | 1.6 (1.8) | 1.0 (1.3) | 2.7 (2.1) | <.001 |
| • My belief that advance care plans are too simplified for complicated medical scenarios | 1.4 (1.3) | 1.3 (1.2) | 1.5 (1.4) | .70 |
| • My fear that these conversations will diminish hope in patients with serious illness | 1.2 (1.2) | 1.2 (1.2) | 1.3 (1.4) | .83 |
| • My belief that physicians are better positioned to do ACP | NA | NA | 1.0 (1.3) | NA |
| • My belief that patients should initiate this type of discussion | 0.9 (1.3) | 0.8 (1.1) | 1.3 (1.5) | .11 |
| • My fear that ACP will negatively affect my relationship with patients | 0.8 (1.0) | 0.8 (1.0) | 0.8 (0.8) | .43 |
| • My belief that it is my job to cure people | 0.6 (1.2) | 0.6 (1.2) | NA | NA |
| Barriers related to physicians as perceived by allied health professionals | | | | |
| • Physicians' lack of time to have conversations with patients and families | NA | NA | 3.3 (2.4) | NA |
| • Insufficient access to or availability of physicians to help with ACP (eg, too busy) | NA | NA | 3.2 (2.2) | NA |
| • Physician not in agreement with me about when to initiate ACP | NA | NA | 2.6 (2.7) | NA |
| • Physicians' desire to avoid conflict or strong emotions that might arise during discussions about goals of care | NA | NA | 2.4 (2.7) | NA |
| • Physicians' lack of communications skills | NA | NA | 2.1 (2.3) | NA |
| Barriers related to patient characteristics | | | | |
| • Patients' difficulty understanding the limitations and complications of life-sustaining therapies (mechanical ventilation, CPR, vasopressors, etc) at the end of life | 3.1 (1.3) | 3.1 (1.3) | 3.1 (1.3) | .45 |
| • Patients' lack of understanding about how treatment decisions are made at the end of life | 3.0 (1.4) | 2.9 (1.4) | 3.1 (1.5) | .88 |
| • Incapacity of patient because of diminished consciousness or dementia or other cognitive disability | 2.9 (1.6) | 2.8 (1.6) | 3.1 (1.6) | .80 |
| • Patients think ACP is not relevant to them because they are too healthy right now | 2.8 (1.4) | 2.7 (1.4) | 3.0 (1.4) | .81 |
| • Patients' fear of upsetting their families by discussing the topic | 2.7 (1.4) | 2.5 (1.4) | 3.0 (1.4) | .66 |
| • Patients' difficulty accepting their poor prognoses | 2.6 (1.2) | 2.6 (1.2) | 2.5 (1.2) | .56 |

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| BARRIERS | ALL, MEAN (SD) | PHYSICIANS, MEAN (SD) | OTHER HEALTH CARE PROFESSIONALS, MEAN (SD) | P VALUE |
|--|----------------|-----------------------|--|---------|
| • Patients not understanding or misinterpreting my reasons for bringing up the topic | 2.3 (1.3) | 2.3 (1.3) | 2.4 (1.4) | .53 |
| • Family unwillingness to support me in engaging the patient in ACP discussions | 2.3 (1.4) | 2.1 (1.4) | 2.6 (1.4) | .22 |
| • Patients' strong religious convictions | 1.8 (1.4) | 1.6 (1.3) | 2.3 (1.7) | .26 |
| Barriers related to the health care system or external factors | | | | |
| • Insufficient time during scheduled appointments to deal with this topic | 3.8 (1.7) | 4.3 (1.4) | 2.8 (1.8) | <.001 |
| • Inability to electronically transfer patients' advance care plan to acute care | 3.5 (1.8) | 3.4 (1.8) | 3.7 (1.9) | .26 |
| • Decreased interaction with my patients near the end of life owing to transfer of care to specialists or others | 3.1 (1.7) | 3.1 (1.7) | 3.2 (1.6) | .96 |
| • Patients getting different messages from the family physician and the other specialists involved in the patient's care | 2.8 (1.5) | 2.7 (1.5) | 3.0 (1.6) | .82 |
| • Limited capacity to honour patients' expectations for care that arise from ACP discussions | 2.6 (1.5) | 2.6 (1.4) | 2.8 (1.6) | .54 |
| • Lack of ready access to forms and resources for patients | 2.5 (1.6) | 2.6 (1.7) | 2.5 (1.6) | .40 |
| • Insufficient access to or availability of other health care professionals (social workers, nurses, or others) to help with ACP | 2.4 (1.7) | 2.5 (1.7) | 2.4 (1.7) | .95 |
| • Lack of financial remuneration for ACP | 2.1 (1.9) | 2.1 (1.9) | NA | NA |

ACP—advance care planning, CPR—cardiopulmonary resuscitation, NA—not applicable.

Table 3. Thematic analysis results of open-ended survey question regarding ways to overcome barriers and make it easier for health care providers in primary care to talk with patients about ACP

| THEMES AND SUBTHEMES | DESCRIPTION | ILLUSTRATIVE QUOTATIONS |
|--|---|---|
| Public involvement <ul style="list-style-type: none"> • Public awareness of ACP • Public engagement in ACP • Public education about limitations of life-sustaining treatments | Respondents mentioned that the public should be made aware of the importance of ACP through media, thought it should be normalized, and suggested that it is a public health issue. There was also believed to be an obligation for all health care providers in the system to ensure that patients are given honest information about life-sustaining treatments | <ul style="list-style-type: none"> • “Perhaps more media attention to the importance of this issue, getting individuals to give this issue priority and to reinforce that ACP is for everyone to contemplate and execute, not just those who are very ill or very elderly” (MD) • “Make ACP a public health issue. Make it the norm for all healthy adults to have this conversation before illness starts” (MD) • “Group visits or neighbourhood forums to discuss the topic” (MD) • “Patients do not realize the a) lack of utility and b) potential for harm of most medical care at end of life; it is an eye opener to share it with them. I worry I sound like a conspiracy theorist when I talk about it and I am the only one they have ever heard it from!” (MD) |
| Health care provider attitudes <ul style="list-style-type: none"> • ACP as a part of family practice • Frank, honest communication with patients | Respondents described ACP as being a part of the role of the family physician in the context of providing patient-centred care in primary care; ACP was compared to routine practices such as cancer screening for preventive health | <ul style="list-style-type: none"> • “Remembering that one of the most important functions of primary care is to act as the patient advocate and care coordinator. End-of-life discussion is an essential part of this management role” (MD) • “Discussion of ACP should be deemed as ‘mandatory’ as cancer screening is for patients on PHR. Setting an age limit on when this gets discussed on a PHR is one way to start the conversation” (MD) |

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| THEMES AND SUBTHEMES | DESCRIPTION | ILLUSTRATIVE QUOTATIONS |
|---|--|---|
| Creating capacity for primary care providers <ul style="list-style-type: none"> • Training • Clarity of roles for MD and AHP | The need for training of family physicians and others in primary care and the need to clarify roles within the primary care practice were described. A particular need for training on how to start conversations was noted. An important role for AHPs was described; AHP noted that there should be a team approach to ACP wherein roles are clarified for the family physician and other health professionals | <ul style="list-style-type: none"> • “Training in ACP. I have never received any training, therefore I do not engage in these discussions” (MD) • “Team training particularly with the multidisciplinary team can be useful with this” (AHP) • “Simple tools to provide to health care providers on how to initiate the conversation on ACP” (MD) • “Have MDs in clinic talk to nurses about how they want nurses to be involved with their patients about ACP. All the MDs have different ideas on who or what to discuss [with] ACP so it is difficult for nurses” (AHP) |
| Integration of ACP into work flow <ul style="list-style-type: none"> • Automation of patient identification • Available resources in practice • Mechanism to document • Mechanism of reminder | Respondents noted a need for automated (electronic) triggers to identify patients and reminders to revisit discussions within the EMR, making ACP resources for patients readily available in the practice, and a mechanism to document discussions | <ul style="list-style-type: none"> • “Having a separate icon in the EMR re ACP; it could even part of [the] physical so that discussion happens with everyone” (AHP) • “Consistency in the forms used and their delivery—I believe this is now happening with the Green Sleeve”[*] (MD) • “Have good-quality handouts available online, in offices, posters everywhere” (MD) |
| System and policy support <ul style="list-style-type: none"> • Transferability of ACP • Remuneration for ACP • Policy support | Respondents provided clear direction on system and policy recommendations, suggesting the need for remuneration through billing codes and incentives that reflect the time that is required, transportability of ACP information throughout the health care system, and the need to monitor and measure the affects of this activity | <ul style="list-style-type: none"> • “We need a common provincial electronic health record with a section specifically for ACP that can be updated in real time by a patient’s health care provider regardless of their location” (MD) • “We need to have time to have these discussions with patients and their families. This translates to the need for remuneration. We cannot forward ACP as a priority if it is not sufficiently funded despite its high level of importance. You get what you pay for” (MD) • “We need some way to capture the benefits of ACP discussions. If you can’t measure it then you can’t improve it. ACP might save the system millions of dollars by reducing unnecessary and unwanted tests, procedures, interventions, etc, that may only further diminish quality of life” (MD) |

ACP—advance care planning, AHP—allied health professional, EMR—electronic medical record, MD—medical doctor, PHR—periodic health review.
^{*}A Green Sleeve is a plastic pocket used in Alberta that holds advance care planning forms and that is intended to travel with the patient throughout the health care system.

care that take account of the potential role of all providers. A systematic review of the role of nurses in ACP in non-primary care settings included 3 studies, reporting that nurses’ confidence was moderate.²¹ It seems there is an opportunity to clarify the role of allied health professionals in ACP and to explore interprofessional team-based approaches to ACP in family practice.

Respondents perceived that patients and families experience difficulty understanding treatment options around the end of life. Studies on end-of-life communication in hospital settings have also found that clinicians perceive patient and family member factors as the most important barriers to goals-of-care discussions, specifically their difficulty accepting a poor prognosis and their lack of understanding of life-sustaining treatments.^{19,22} The findings underscore the importance of incorporating tools and resources that assist with integrating ACP into practice, such as general ACP information and decision aids to increase knowledge about life-sustaining treatments.²³ It will also be important to

ensure that health care professionals in primary care have appropriate communication skills training for ACP conversations.^{24,25} Practice resources to assist with conversations exist in Canada and elsewhere.^{24,26,27}

Strengths and limitations

The study has several strengths. Primary care providers in 3 provinces, reflecting team-based and non-team-based family practices, were included. The survey instrument originated from one previously shown to have content validity and clinical sensibility,¹⁹ which we further developed with input from and pretesting by both family physicians and other health professionals in primary care. The study also has limitations. The sample comprised volunteers who responded to advertised invitations or a request while attending a meeting, although among this group there was a high response rate. Participants might have different views on ACP than clinicians who did not participate.

Conclusion

Given the multifaceted nature of the barriers and enablers identified, it is likely that to achieve higher engagement in ACP, strategies will be needed at multiple levels that target the public at large, patients (and families), clinicians in family practice, and the health care system. With knowledge of the barriers and enablers that are specific to primary care, targeted strategies to integrate ACP into routine primary care can be developed to achieve the positive outcomes of meaningful engagement in ACP. 🌿

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Contributors

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Competing interests

None declared

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