

Initiating Advance Care Planning Discussions in Community–Dwelling Elders: Barriers and Facilitating Factors Influencing Family Physicians

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Citation: UBCMJ. 2019; 11.1 (19-22)

Abstract

Objective: Advance care planning (ACP) allows patients to communicate their goals for future care. This is ideally completed when patients are still competent enough to make their own decisions, such as in the primary care setting. We aimed to explore common facilitating factors and barriers influencing family physicians (FPs) in initiating ACP discussions with community–dwelling elders.

Methods: Semi–structured interviews were conducted with a convenience sample of 13 FPs practicing in Vancouver, Canada. Interviews were analyzed using thematic analysis.

Results: FPs were more comfortable initiating ACP if they had a close relationship with the patient, if they were familiar with ACP terminology, and if the patient or family was willing to talk about death and dying. Most physicians felt impending death facilitated discussion, whereas a few physicians found that it made discussions more difficult. FPs often found it difficult to communicate the content of ACP discussions from office–based community practices to the hospital setting. A lack of time and of a concise framework hindered ACP initiation. We noticed that numerous ACP resources exist but may be unknown or inaccessible to physicians. FPs also commented on a lack of effective non–English ACP patient handouts.

Conclusions: The self–identified barriers and facilitating factors influencing FPs' decisions to initiate ACP were remarkably diverse and occasionally contradictory. There is a need for improved communication between healthcare providers, greater public awareness of end–of–life issues, and increased accessibility and awareness of ACP resources, especially in non–English languages.

Introduction

Advance care planning (ACP) allows patients to communicate their healthcare wishes to providers in the event that they are unable to make decisions for themselves. Numerous studies have shown the benefits of ACP in a variety of chronic diseases including dementia, HIV, cancer, and congestive heart failure.^{1–3} Among these, ACP may have the greatest potential to influence the care of the elderly, a population accounting for 80% of total deaths in Canada.⁴

Current literature supports early initiation of ACP among the elderly as they are at risk of sudden functional decline.^{5,6} Although most elders engage in end–of–life care planning upon admission to a long–term care facility, data show that less than 36% of nursing home residents have the capacity to engage in these discussions.^{3,7} It is important to initiate ACP with elders prior to entering residential care and while they can still actively participate in future care planning.

Family physicians (FP) are optimally placed to initiate early ACP discussions due to their longitudinal relationships with patients. They have been identified as patients' preferred person to discuss ACP topics such as resuscitation.⁸ Furthermore, the most effective interventions to increase the completion of living wills involve direct patient–physician interaction over multiple visits, which can easily be accomplished in the office setting.⁹ However, only 17.5% of older adults engaged in ACP activities have involved their FP.¹⁰

The purpose of this study is to identify barriers and facilitating factors that FPs face when initiating ACP discussions with their elderly patients. We hypothesized that the lack of ACP resources may be a potential barrier, and thus wanted to research current and ideal educational materials FPs would want to access. For the purposes of this paper, the terms Advance Care Planning (ACP) and End–of–Life

(EOL) Planning will be used interchangeably.

Methods

Design

We conducted semi–structured interviews using a standard interview guide (Table 1) with local FPs working in the Greater Vancouver Region, Canada. Interviews were recorded, transcribed, coded, and analyzed for themes. This paper focuses on the data collected from the barriers and resources aspect of the interviews.

Table 1 | Interview Guide.

Who / Where	<ul style="list-style-type: none"> • What role do you think FPs should have in ACP in elderly patients? • How comfortable are you with discussing ACP with elderly patients?
What / How	<ul style="list-style-type: none"> • What does ACP for elderly patients (>65 years old) look like in your practice? • What topics do you talk about? • How frequently do you follow up with the ACP decisions over time, if at all?
When	<ul style="list-style-type: none"> • When do you decide to have ACP discussions with your elderly patients?
Why	<ul style="list-style-type: none"> • What effect did ACP have on your patients?
Barriers / Resources	<ul style="list-style-type: none"> • What kind of influences help or hinder your decision to talk about ACP with elderly patients? • Are there any resources/educational materials you find useful? • What would you want to know to help facilitate discussions on ACP?

Ethics approval was obtained from the University of British Columbia's Behavior Research Ethics Board (H16-00044).

Sample Selection

A convenience sample of FPs practicing in the Greater Vancouver Region was recruited from family practice rounds at a local hospital, as well as from a list of 48 FPs participating as first–year medical student preceptors.

Data Collection

All participants provided written consent for their participation. Interviews were conducted between May and June 2017. Nine interviews were held in person and four interviews were carried out by telephone. All interviews were conducted by the same investigator (IJ) using the standardized interview guide. Twelve of thirteen participants consented to voice recording. For the remaining participant, the investigator took

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notes throughout to ensure main discussion points were captured.

To analyze the accessibility of ACP resources, physicians were asked about specific tools they used to educate patients on ACP. We attempted to locate less common ACP resources, defined as any resource excluding My Voice, Medical Orders for Scope of Treatment (MOST), and Do Not Resuscitate (DNR) forms, within the first five pages of the Google search engine. My Voice is a 56–page ACP booklet created by the BC Ministry of Health and is often used by FPs to educate patients and families.¹¹ MOST is a form indicating the level of care the patient wishes to receive with regards to CPR and intubation. DNR is a form indicating patient refusal of resuscitation in the event of a pulmonary or cardiac arrest.

Data Analysis

The recorded interviews were transcribed, checked for accuracy, and inductively coded. Two researchers (IJ and JH) independently analyzed the transcripts using open coding. Comparable codes with similar content were grouped into themes and the researchers discussed differences until consensus was reached. Data consolidation was supported by NVivo 11 qualitative data analysis software (QSR International Pty Ltd). Two other investigators (JK and MM) reviewed the final analysis and verified the themes.

Table 2 | Participant Demographics (n = 13).

*Two doctors provided a range of 40–45 years old for their age category, and the average of 43 years was used in the median calculation.

Gender	Male: 9 (69%) Female: 4 (31%)
Mean age*	47 years (SD 10; range 30–61)
Ethnicity	Caucasian: 9 Chinese: 2 Korean: 1 Japanese: 1
Years in practice	17 (SD 11; range 3–36)
Type of practice	FP office: 12 Nursing home: 5 Hospital: 5 Community health center: 2 Rural practice: 1
Estimated % elderly in their practice	23 (SD 17; range 5–50%)
Education about EOL care	None: 8 One-time workshop: 4 >One-time workshop: 1
Self-rated comfort level with discussing ACP with elderly patients	Very comfortable: 7 Relatively comfortable: 5 A little more comfortable than start of career: 1

Results

A total of 13 family physicians were recruited into this study (Table 2); twelve were recruited via email from a first-year medical student preceptor list at the University of British Columbia and one from family practice hospital rounds at Vancouver General Hospital. The participants' mean age was 47 years old and 77% of participants practiced in more than one setting. Twelve participants were fee-for-service and two participants had hospital privileges. There was a greater proportion of Caucasian (69%) and male (69%) participants. Although the study was not designed for ongoing sampling, saturation point was reached with a sample of 13 participants. The average interview duration was 20 minutes (range 7 to 38 minutes).

Factors identified fell under four themes: patient/family specific traits; physician comfort level; system-level restraints; and ACP resources (Table 3). All themes where participants showed conflicting opinions are presented in Table 4.

A) Patient/Family Specific Traits

FPs had a difficult time initiating ACP if the patient or family was uncomfortable or not receptive with the topic, even if they were well versed in holding this conversation. This is illustrated in the following quotations:

“I tend to shy away from [following up with ACP discussions] if my patients are uncomfortable with it. I try to float it out there in a comfortable normal way the first visit but if they don't want to talk about it I tend not to bring it up in subsequent visits.” (Interview 1)

“I see a lot of barriers from family members with sick loved ones who are very firm and say ‘No, you have to do everything for Mom.’” (Interview 11)

Table 3 | Frequency of Themes Mentioned in Interviews.

Factor	Theme	Interview Mentioned
Patient/family specific traits	Barrier: patient/family not receptive	1, 2, 3, 4, 9, 10, 11, 13
	Facilitating factor: patients initiating the ACP conversation	1, 2, 11, 12
	Barrier: non-English speaking	11
Physician comfort level	Barrier: cognitive impairment	11, 12
	Barrier: weak patient-physician relationship	9
	Facilitating factor: strong patient-physician relationship	3, 4, 9, 12
	Barrier: ACP terminology	11
	Barrier: increased risk of death (e.g., older age, deteriorating health status)	7, 9
System-level barriers	Facilitating factor: increased risk of death (e.g., older age, deteriorating health status)	1, 3, 4, 5, 6, 10, 12, 13
	Barrier: lack of time	1, 7, 8, 9, 10, 11, 12
	Barrier: information transfer	7, 8, 9, 10, 11
ACP resources	Barrier: lack of effective ACP resources	9, 10, 11
	Facilitating factor: effective ACP resources	1, 7, 10

Table 4 | Examples of Conflicting Perspectives.

Influencing Factor	Interview Illustrations
Older age of patient	Easier Conversation It is more routine in older patients because we feel more comfortable and they feel more comfortable talking about end of life. (Interview 1)
	Difficult Conversation It's hard to bring it up. I think the older they are, the harder...Once they are past 85, it's hard to bring up because they know it's imminent. (9)
Deteriorating health status	Easier Conversation If they are dying they need to know. They need to get things prepared and things in order. (3)
	For people who don't have these co-morbidities or they're not frail...it becomes a hard discussion to have. (6)
My Voice as an effective resource	Difficult Conversation [If] they're healthy and well, it's sort of an easier conversation. But if they're actually sort of on the slippery slope of decline, I find it more difficult to initiate actually. (7)
	Useful I use the My Voice brochure, I use it all the time. If I'm going to have a conversation, I will direct them to that. (7)
	My Voice gives good background information and gives them a chance to do some homework. (10)
	Difficult to Use My Voice is daunting, it's too big, it's too long. It's got good information in it but I don't know if they could somewhat revamp it, differently, make it smaller. (12)
	The English version takes someone with a college degree to understand, like seriously, you and I would be reading the English version and you would have to concentrate to understand it. So fat chance that your average 65–70-year-old retiree will get through, not to mention there's a language barrier...You can't navigate it as a patient. (9)

Conversely, several physicians mentioned that they will definitely hold these discussions with patients who initiate the topic, even if it is with a demographic they do not normally approach. For example:

“If somebody brought it up to me, I would absolutely have the conversation with them.” (Interview 12)

Language barriers and cognitive impairment were also factors that hindered the ACP discussion (Table 3).

B) Physician Comfort Level

Physician comfort level in conducting ACP discussions was influenced by the depth of the patient–physician relationship. Multiple participants stated that they felt more comfortable initiating difficult conversations with patients whom they had a strong relationship with. This is best illustrated in the following quotation:

“My practice is bimodal because half of my practice followed me from my old clinic and I have some patients who joined me recently, so I don’t know them as well. It’s the same demographic in terms of age and ethnicity, so I find it much harder to bring it up with my newer patients.” (Interview 9)

Physicians’ familiarity with ACP terminology and paperwork also influenced their willingness to broach the topic. One participant mentioned that different terminology used between different health authorities led to substantial confusion. Lastly, some physicians found it easier to initiate ACP when death was more imminent, whereas other physicians found it difficult for the same reasons (Table 4).

C) System–Level Barriers

Lack of time was commonly cited as a prominent barrier, especially in a fee–for–service environment. This is illustrated in the following quotations:

“At one point, I tried to have this discussion with everyone regardless of age; for all of my patients greater than 65 years old, I’m going to try to have an advance directive on file, so I just started doing that. But it was just so time consuming that I gave up.” (Interview 7)

“I guess remuneration is an issue, we don’t get paid to have these conversations. If we have a separate billing to do this, we would do it.” (Interview 12)

Physicians were also unsure about the impact of ACP due to issues with implementation. This was largely due to ineffective information transfer between office–based community practices and hospital environments, as seen in the following quotation:

“I don’t find the documentation part gets translated or used appropriately...Certain hospitals, upon admission, will send a one–page fax asking for any and everything you have...and you have a feeling that the information you carefully compiled for them is actually not going to get looked at.” (Interview 9)

D) ACP Resources

FPs frequently used MOST and DNR forms (85%) as well as the My Voice document (54%) to initiate ACP discussions. We found varying opinions regarding the utility of the My Voice document due to its length and complicated language (Table 4). We also realized that there is a lack of effective non–English resources, as all resources existed solely in English with the exception of My Voice, which appeared to be poorly translated, as illustrated in the following quotation:

“The Chinese version of My Voice, it was very awkwardly translated, it’s horrible. I mean I’m fluent in Chinese and I read

it, and I have to read it three times to know what they’re [saying].” (Interview 9)

Some physicians also cited the lack of an effective and concise ACP discussion guide as a barrier to discussion. This is illustrated in the following quotation:

“I think it would also be nice if there was a template that could help direct this conversation, to keep the conversation concise and focused because sometimes the conversations get side–tracked just because of the breadth and depth of it.” (Interview 7)

The investigators also collected information on resources other than those mentioned above, including resources physicians used to initiate ACP discussions (Table 5) and the types of resources they felt were missing from practice (Table 6).

Table 5 | List of Current Resources Specific to ACP Mentioned by Physicians.

Resource mentioned	Interview #	Ability to locate within 5 search pages
Vancouver Coastal Health pamphlet on Cardiopulmonary Resuscitation	1	Yes
Dementia roadmap	1	Yes
North Shore Palliative group	10	Yes
Fraser Health Options of Care pamphlet	11	No
Dr. R. Gallagher’s YouTube video on ACP and death and dying from Pathways BC website	11	No
The GP Services Committee video on role-playing with RNs for difficult EOL conversations	12	No

Table 6 | List of Ideal Resources Specific to ACP Mentioned by Physicians.

- One–page ACP framework/template about critical questions to ask (Interviews 5, 7, 8)
- Printable shared decision aids (Interview 11)
- Knowing what other colleagues do (Interviews 1, 5, 6, 7)
- Tools for cultural literacy (Interview 1)
- List of programs and resources, including affordable nursing homes and home support (Interviews 2, 4)

Discussion

This study revealed that a remarkably diverse and occasionally contradictory number of factors influenced ACP initiation among a convenience sample of FPs, most of whom lacked formal ACP training.

All participants found it easier to initiate EOL care discussions with patients or families who were open to talking about death and dying. FPs also indicated that they would discuss ACP with patients they would not normally approach if patients brought up the topic themselves. This is consistent with other findings, and highlights how delivering quality palliative care requires engaging in a broader discussion about cultural taboos on death and dying.^{12,13} Although only one of the participants mentioned cognitive impairment and lack of English proficiency to be barriers, these factors have been established in the literature to be significant obstacles to ACP.^{14–16}

While all participants were moderately comfortable with initiating ACP discussions, several factors influenced their willingness to approach this topic. Factors that decreased FPs’ comfort levels included differences in ACP terminology across health authorities and the lack of a strong connection with the patient. Interestingly, there were conflicting responses to whether impending death, as indicated by older age or deteriorating health status, facilitated or hindered the ACP conversation. This suggests that individual practitioner traits have a significant impact on perceived barriers.

Time constraints and ineffective communication between office–based community practices and hospital environments were

significant systemic barriers.^{12,13,17,18} The majority of our participants were compensated on a fee-for-service basis, and commented that it became difficult to address ACP in a single visit due to the breadth of the discussion and other priorities of care. While literature has shown that ACP has multiple benefits for the elderly population—including improved quality of dying, decreased family stress and anxiety, and reduced hospital admissions and length of stay—participants doubted the utility of ACP.^{19,21} Office-based FPs often did not have a clear understanding of how ACP affected patient care due to transfer of patient care near end of life.¹³ In contrast, they were often aware of situations where mutually established advance directives were not implemented due to issues with information transfer. There is a lack of a standardized method to transfer ACP information from office-based community practices to hospitals, and patients are assumed to be full code unless legal documentation can be provided. From our interviews, FPs often conveyed patients' documented wishes through phone communication with the hospital physicians or through fax, but practices varied widely depending on the physician responsible and on hospital policy.

In response to difficulties with communicating patients' EOL wishes to hospitals, physicians proposed two solutions: increase accessibility to forms via creation of a central data storage system, and/or focus on educating the patient and family. The latter approach calls for patients and their families to take charge of essential documents and to voice goals of care to other providers. In lieu of a centralized system, proper patient and familial education is an important solution to communication issues at this time.

This study also addressed available and ideal ACP resources. Although My Voice is a commonly used ACP resource, some physicians found the length, reading level, and non-English translations inappropriate for most audiences. Given the significant diversity of urban populations, virtually all FPs in Canadian urban settings will encounter patients with alternative first languages. Our study showed a need for culturally competent, multilingual ACP resources.

We found that numerous ACP resources exist but were not well known or accessible.²² For example, several physicians expressed interest in resources illustrating how other health care providers conduct ACP discussions, which do currently exist. Furthermore, multiple FPs were unaware that advance care directives were available online at advancecareplanning.ca, despite this website being a central nation-wide resource. This has implications for new and current ACP resources, such as the ACP framework developed by Dhillon et al., which may have poor uptake.²³

Strengths and Limitations

This study provides an updated perspective on the perceived barriers and facilitating factors influencing FPs in their role in ACP. Strengths of this study include holding one-on-one interviews with participants and a focus on community-dwelling elders.

Our major limitation is our small convenience sample size of Canadian urban-based physicians, most of whom are involved in undergraduate medical education and do not have formal ACP training. Physicians who had prior interest or participation in ACP discussions may have had increased willingness to participate, potentially limiting the generalizability of our findings. Participants also frequently worked in more than one setting, and thus, study findings may not reflect the opinions of FPs working solely in the clinic setting.

Future Directions

Given the findings of our study, we have a few suggestions for future projects on ACP in the primary care population. To improve patient and family receptivity, there is a need for increased public awareness on palliative care and its benefits. This can be accomplished through a variety of modalities, including public conferences and outreach programs. Given the important role of families in communicating

patients' EOL goals across care settings, it would be beneficial to explore family members' understanding of advance care plans when a patient presents to hospital. This can be conducted through surveys or focus groups and will help identify important teaching points to increase implementation of advance care plans. Lastly, we recommend the creation of succinct, non-English patient information resources and a handout outlining the different ACP terminology used across various health authorities.

Conclusion

We found that FPs' self-identified barriers and facilitating factors influencing their decision to initiate ACP were remarkably diverse and occasionally contradictory. We identified common barriers hindering ACP, including patient and family unwillingness, lack of familiarity with ACP terminology, time constraints, and difficulty with information transfer. Our research highlights a need for improved communication between healthcare providers and for increased public awareness on EOL issues. There is also a need for increased accessibility and awareness of ACP resources, especially in non-English languages.

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