'Not yet' and 'Just ask': barriers and facilitators to advance care planning—a qualitative descriptive study of the perspectives of seriously ill, older patients and their families

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ABSTRACT

Objectives To explore seriously ill, older hospitalised patients' and their family members' perspectives on the barriers and facilitators of advance care planning (ACP).

Methods We used qualitative descriptive study methodology to analyse data from an interviewer administered, questionnaire-based, Canadian multicentre, prospective study of this population.

Results Three main categories described these barriers and facilitators: (1) person (beliefs, attitudes, experiences, health status), (2) access (to doctors and healthcare providers, information, tools and infrastructure to communicate ACP preferences) and (3) the interaction with the doctor (who and how initiated, location, timing, quality of communication, relationship with doctor).

Conclusions Based on the findings, we suggest strategies for both healthcare systems and individual healthcare providers to improve the quality and quantity of ACP with this population. These include assessing readiness for participation in ACP and personalising relevance of ACP to each individual, routinely offering scheduled family meetings for exploring a person's own goals and sharing information, ensuring systems and policies are in place to access previous ACP documentation and ensuring doctors' education includes ACP communication skills.

INTRODUCTION

Advance care planning (ACP), the process of reflecting on and communicating a person's wishes and goals for their future healthcare, offers patients the potential to inform and guide their medical therapy even when they lose capacity for medical decision making. As such ACP may help us navigate through the current dilemma of healthcare, which is that advances in medical technology can prolong life beyond our ability to consent to or decline such treatment.[1 2] ACP has been found to have a number of benefits: it is associated with better patient quality of life during the terminal phase, better outcomes for family caregivers and a less resource-intensive care pathway at the end of life.[1 3–7] A low percentage of the general population within Canada, however, has undertaken ACP or included important elements such as discussing plans with a healthcare provider and formally documenting a surrogate decision-maker or their wishes for healthcare in a document such as an advance directive.[8]

It can be anticipated that older, seriously ill adults will face critical decision making about the goals and interventions of their medical therapy in the final months and years of life and that these patients have much to gain from ACP.[4] The Advance Care Planning Evaluation in Elderly Patients (ACCEPT) study, a Canadian, multicentre, three-cycle audit-feedback prospective study,[9] seeks to assess the quantity and quality of ACP from these patients' and their family members' perspectives. Quantitative findings from the first audit cycle found deficits in the frequency and content of communication between clinicians and patients/family members and a worrying lack of concordance between patients' stated preferences for life-sustaining therapies and their medical orders directing the use of these therapies.[9] ACCEPT has

also explored the barriers and facilitators that patients and their family members describe to participating in ACP, with the objective of informing policymakers, health administrators and clinicians on strategies to improve engagement. Here we present the qualitative findings of those barriers and facilitators.

METHODS

The ACCEPT methods are described in detail elsewhere.[9] In brief, we examined the data from the first audit cycle conducted at 12 acute-care hospitals in Canada. The enrolment criteria included hospitalised patients aged 55 years and over with advanced cardiac, pulmonary, liver disease, dementia or metastatic cancer or those aged 80 years and over admitted for an acute medical or surgical reason. If neither of these criteria were met, patients aged 55 years and over, whose death within the next 6 months would not be a surprise to any member of his or her healthcare team, were also eligible. These criteria define a patient population at high risk of dying in the next 6 months. Enrolled study patients were asked to identify, if applicable, an adult family member who knew

them best (inclusive of partners, significant others and close friends), had visited the patient in hospital at least once, had provided the most care to the patient and was not paid to do so. Patients unable to communicate due to language (interviews were only in English or French) or cognitive reasons (assessed subjectively by attending staff or the research assistant) were excluded from the interview, but if their family member was eligible and available then they were approached independent of the patient.

At each site, patients and family members were interviewed face-to-face separately and alone by research assistants. The research assistants recorded each participant's verbal responses in writing on the questionnaire, with the instructions, 'When the question is open-ended, do not paraphrase or change the respondent's answer. Record the answer verbatim.' Life-sustaining therapy was defined in the questionnaire (see box 1), and research assistants were able to further explain medical terminology as needed for the respondents during the interview. There was no fixed glossary of terms. Interviews took place between 48 and 120 h after hospital admission to allow for

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Box 1 The nine open-ended questions asked within the ACCEPT questionnaire

The wording for the family member questionnaire is shown in italics.

1. Do you (*Does your relative*) have an advance directive or living will or some other written document describing the medical treatments you (*s/he*) would want (or not want) in the event you are (*s/he is*) unable to communicate for yourself (*himself/herself*) as a result of a life-threatening health problem? If No, why not?

2. Have you ever considered or thought about what kinds of life-sustaining treatments you would want or not want (*for your relative*) in the event your physical health deteriorated? By life-sustaining treatments, we are referring to the use of cardiopulmonary resuscitation (CPR), breathing machines, dialysis, intensive care unit (ICU) admission, etc. If No, what are your reasons?

3. I note that prior to hospital admission you have not discussed your wishes concerning the use of CPR and other life-sustaining treatments in the event your physical health deteriorated, or you developed a sudden life-threatening condition, with a doctor. What are the reasons for that?
   I note that prior to hospital you have not discussed the use of life sustaining treatments in the event your relative developed a life-threatening condition with her/his doctor. What are the reasons for that?

4. I note that prior to hospital admission you have not discussed your wishes concerning the use of CPR and other life-sustaining treatments in the event your (*your relative's*) physical health deteriorated, or you (*s/he*) developed a sudden life-threatening condition with your partner, family or surrogate decision-maker (*him/her or other family member*). What are your reasons?

5. In general, what kinds of things make it difficult for you to talk with your (*relative's*) doctors and healthcare professionals prior to hospital admission about your (*or your relative's*) plan of care including discussion about your (*his/her*) prognosis and the use of life-sustaining treatments in the event your (*his/her*) condition deteriorated?

6. What kinds of things make it easier for you to talk with your (*relative's*) doctors and healthcare professionals about these same concerns?

7. Was there anything we could have done differently to improve the process of making a decision about medical treatments to sustain life in the event your (*relative's*) condition deteriorated?

8. In general, what kinds of things make it difficult for you to talk with your (*relative's*) doctors and healthcare professionals in-hospital about your (*relative's*) plan of care including discussion about your (*his/her*) prognosis and the use of life-sustaining treatments in the event your (*his/her*) condition deteriorated?

9. What kinds of things make it easier for you to talk with your (*your relative's*) doctors and health care professionals in-hospital about these same concerns?

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symptoms present at the time of admission to have abated enough for the patient and family to participate.

The questionnaire explored ACP activities during two time periods: before the current hospitalisation and since the admission to hospital. It included a mixture of quantitative, closed-ended response questions[9] and nine questions that elicited qualitative, open-ended responses. It is the responses to these nine open-ended questions (box 1) that are analysed here. Four of the questions were asked only of participants who had not completed a given element of ACP, eliciting their reasons, 'Why not?' All participants were asked the remaining five questions that inquired about the barriers and facilitators to communication about the patient's plan of care, prognosis and use of life-sustaining therapies, with their doctors and healthcare professionals, in the periods before and since hospitalisation. Family members were asked about their wishes for the patient, not a proxy assessment of patient wishes.

The interviews were conducted by more than 12 research assistants, and completed questionnaires were transcribed into a database. Three other researchers conducted the data analysis (PP, SR, JS). A qualitative descriptive study design[10] was used to gain a deepened understanding of the barriers and facilitators to engaging in ACP through the patients' and their family members' responses. The qualitative descriptive study draws from naturalistic inquiry[11] grounded in people's lived experiences that focus on context and is emerging and evolving. Qualitative descriptive analysis is the analysis of choice in qualitative descriptive studies orientated towards summarising the informational contents of the data.[10] The goal of the analysis is a descriptive summary of the informational content of the data organised in a way that best fits the data. The data from the open-ended questions were coded and arranged into categories. Coding occurred in three phases, which are labelled as descriptive, interpretive and explanatory.[12] *Descriptive* coding occurred first with the three researchers, independently and then collectively, coding every response to identify coding categories. The aim was to keep the language of the categories similar to the original words used by the participants, moving from raw data recorded from patient/family responses to abstract ideas and concepts. Data were also read in its entirety by each researcher, and memos were created to clarify the categories. To ensure accuracy, we filled out data summary tables as we coded and memoed about certain occurrences or sentences that seemed of vital interest. This allowed us to capture new descriptors as they emerged and to conceptualise and build a schematic figure. Memoing kept the researchers on track and made sure that the codes came from the data, allowing it to speak for itself. Thus, we began to use *interpretive* coding to connect significance and consequence to the participants' explanations. Saturation occurred when the categories that emerged did not provide further insight into the category and its elements. Finally, *explanatory* coding allowed us to hypothesise connections about the significance of certain outcomes, consequences, interconnections and interrelationships that were emerging about ACP and in-hospital decision making.

RESULTS

The questionnaire was completed by 503 respondents (278 patients: mean age 80 years, 52.9% female; 225 family members: mean age 60.8 years, 75.9% female). We analysed and coded 1575 responses (not all respondents provided open-ended responses for every question). Most of the survey questions concerned *discussions* between patients, family, doctors and other healthcare professionals. There was one question about *documenting* and one question about *thinking* about what kinds of life-sustaining treatments the respondent would want (box 1). In general, most patients (76.3%) and families (81.7%) had *thought* about this, so only a small proportion of participants were directly asked the question, 'What are your reasons?' for *not thinking* about this. Similarly, approximately half of the patients (47.9%) and families (52.2%) indicated that the patients had documented their wishes, so only half were asked about why they had not documented. Nonetheless, the participants' personal attitudes to *thinking about* or *documenting* ACP were also evident in their answers to questions about participating in *discussions* with others. In addition, although the questions varied by time frame (either before hospital or during hospitalisation) and whether it was the patient or family responding, the contents of the responses were similar. Some people would respond to a 'What makes it easier?' question with their own experience of a barrier, and others asked about 'What makes it difficult?' would respond with an answer about what they had found easy or thought would make it easier. A striking finding from the analysis therefore was the repetition of content across all responses, almost regardless of the question asked. Overarching categories describe the elements that contribute to whether or not patients and their family members engage in ACP. The three major categories that emerged were (1) the person (patient or family respondent attributes), (2) access to doctors and ACP resources and (3) the interaction between the doctor and the patient/family. Although the open-ended questions asked about 'talking with doctors and healthcare professionals', most respondents only answered about their interaction with doctors. This is why our model contains the interaction between doctors, patients and families as opposed to other healthcare providers. The categories, their elements and the relationship between them are shown in figure 1. Below, we

describe these categories in detail and in a table for each category (tables 1–3) we provide illustrative quotes by the patient (P) or family (FM) for the elements, which can serve either as facilitators (F) or barriers (B) to discussion.

Person

Respondents (patients and family members) described personal beliefs and attitudes such as 'optimism' or 'fear of death' as reasons not to engage in ACP. For some patients or families, the barrier was the emotional response to reflecting on death, described as feeling 'too emotional' and 'being upset thinking about death'. Beliefs such as faith in God or in family making decisions or that doctors will make the right decision on a patient's behalf without their input, also emerged. However, the most common response was 'never thought about it'. Upon further analysis, 'never thought about it' was not used literally to describe 'not thinking' but was often linked with timing: 'not sick enough', 'not at that point', 'not yet', 'just have not got around to it' or 'will now'. All of these responses convey that some patients and families believe there is a 'right' time, seemingly related to health status and age, for these conversations about the use of life-sustaining therapies. These personal beliefs and attitudes were evident in the responses to thinking about, engaging in discussions and documenting.

Conversely, many patients and families expressed their personal comfort with the topic, describing themselves as 'realistic' and 'open'. Personal experiences such as prior cardiopulmonary resuscitation (CPR) also influenced their willingness to have the discussion. 'I would just tell them. I have nothing to hide. I had a heart attack 2 years ago when I was in hospital for colon cancer surgery. They broke my ribs doing CPR. I had an awful time recovering and I do not want that again. No CPR and no breathing machine.'

Access: to doctors and ACP resources

Most important to persons was access to doctors willing to have these conversations. Repeatedly, patients expressed this access as an enabler or a barrier. Lack of access to a doctor took many forms, including the common response of no access to a community doctor ('no GP') or a lack of clarity as to who was the appropriate doctor in hospital. Families emphasised the access challenges as they often did not accompany their family member to community appointments, thus did not know the general practitioner (GP), or the doctors in hospital were not readily available to them.

Respondents also identified the need for access to information: about ACP generally, the specific forms to use and the burdens or benefits of life-sustaining treatments, such as CPR. The need for portable tools to ensure continuity of care related to ACP was also mentioned. These facilitators were described in the context of respondents reflecting on how the ACP process could be improved and were based either on their hypothesis as to how to create a good experience or their actual experiences with the process.

Interaction with doctor

Key factors in the interaction were who initiated it, location and timing, relationship with the doctor and quality and ease of comprehension of communication. Initiation of the discussion by the doctor was seen as a major enabler. Frequently stated by patients and families was the notion of 'Just ask!', indicating that they would respond to the doctor if the issue was raised. Some patients and families stated a preference to have the conversations with known and trusted doctors (also mentioned in 'access' above), but for others, unfamiliar doctors could establish themselves through their communication skills. At the very least, patients hoped that doctors would respond if they tried to initiate the conversation. One patient did not raise the issue to avoid upsetting their doctor. 'My doctor is religious; it upsets him so we don't discuss
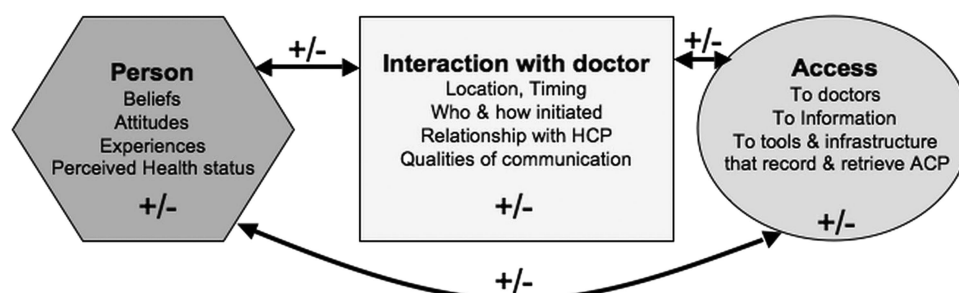
Figure 1 Schematic of the barriers and facilitators to engaging in advance care planning experienced by patients and family members.

Table 1   Person: beliefs, attitudes, experiences and health status influencing engagement in ACP

Person's beliefs and attitudes	Facilitator (F) or barrier (B)	Illustrative quotes
Attitude towards thinking, discussing and documenting about medical treatments, particularly related to death and dying	(F) Ease with the topic of future medical treatments, including end-of-life care	'I don't have a problem talking about this; life is life; you need to take it as it comes.' (P) 'I don't have problems—I am straightforward and find most doctors to be straight forward too.' (FM)
	(B) Discomfort with the topic of medical treatments, in relation to end-of-life	'I don't like to think about dying. I guess if he asked I would talk about it.' (P) 'My need for control. My emotions. I don't like to be emotional.' (P) 'Angst. Feeling of uncertainty, fear of dying, fear of making a plan.' (FM)
Beliefs as to whether engaging in ACP is appropriate or beneficial	(F) Topic is important for me; belief may be based on personal experiences with life-sustaining treatments	'My GP and I talk about these things on a regular basis. After my surgery for oesophageal cancer 15 years ago, I told him not to keep me alive if things didn't go well in the surgery.' (P) 'My background—nursing in neurosurgical hospitals-taught me how I did not want to die.' (FM)
	(B) Topic is not appropriate or necessary for me and best left in the hands of others	'You have to have faith in what you do. Leave all things to the Almighty God.' (P) 'Why should (I) talk with the doctor when family all know (my) wishes?' (P) 'I wouldn't be comfortable talking to her doctors as she is competent to do that herself if she is willing.' (FM)
Beliefs about the relevance of ACP and the person's perceived health status/prognosis/age	(F) Belief that the topic is relevant given age, health status or prognosis	'We are getting old and starting to 'wear out' so it is just natural to take care of these things so our children know what to do.' (P) 'Face the facts, it's life. We have had on-going discussions with his doctors every time his health deteriorates. His GP told us he was a walking time bomb.' (FM)
	(B) Belief that the topic is not a priority or irrelevant while person perceived as healthy, prognosis too uncertain or that mode of death won't need discussions	'No need to, because I was in good health. I am 83, but slowing down and still playing golf. It hasn't been a priority.' (P) 'We keep talking about it—just haven't done it yet.' (P) 'Wanted to wait until I heard what his prognosis was first and then find out about the pros & cons of various treatments.' (FM) 'Assume that one day she will pass peacefully in her sleep.' (FM)

ACP, advance care planning; FM, family; GP, general practitioner; P, patient.

it. Don't want to upset him.' Location and timing of the conversation were another recurrently reported element. Respondents noted the stress that ensued if doctors first broached medical decision making during a health emergency. This appeared to be both due to geographical constraints (noise, absence of family members or lack of privacy) and the stress of being in the health crisis context during which conversations and sudden decision making had to occur.

Honest, open and understandable communication was valued. The desired *content* of communication was around prognosis and potential outcome of treatments: 'You want to know what they can do upfront so we can ask questions'(FM). This notion of upfront information was important as providing decisional context and time for family discussion. Consistency in communication from doctors was also valued, 'Different doctors thought differently about the decision to reveal the information…doctors need to come together on this' (FM).

The need for doctors to focus on the outcomes of treatments, including palliative care, not just on the offer of a medical intervention is clear in the following notable quotes:

I didn't know what he (MD) was saying when asking me when I was in the ER. Do I want CPR? He asked with no explanation. I said 'sure if it works'. He put down YES on the form, but then told me it probably wouldn't work and I would have brain function problems. Good God! I don't want that! Give me the information first, then ask the questions! (P)

I don't have enough information about his condition, what to expect and how long he has. I am trying my best but I don't have a medical background and I am alone in all this decision-making and feel overwhelmed. They ask me about CPR and I said to try and if it doesn't work then let him go. He wouldn't want to suffer. I mean what would they do? Just stand by and let him suffer and die and do nothing? (FM)

Table 2 Access to doctor and ACP resources influencing engagement in ACP

Element of access	Facilitator (F) or barrier (B)	Illustrative quote
Access to doctor and/or other healthcare providers	(F) Organised access to GP/doctors in hospital or other healthcare providers willing to engage in ACP	'If there was some way to be given a number to call at a convenient time than to wait for them to show up.' (FM) 'We used to have family meetings at X [previous living location] including social workers, MDs, RNs. We discussed where we are going with treatment and prognosis. It would be helpful to schedule a family meeting to discuss.' (FM)
	(B) Lack of access to GP or lack of clarity as to who to approach in hospital	'My GP moved 20 km away and it is too difficult and too expensive to get there. I need a new GP.' (P) 'I haven't seen my family doctor and I haven't brought this up in hospital. I also don't know who my doctor is.' (P) 'Nurses are more available but not the ones who I can talk to about this.' (FM) 'I don't usually go to the GP with her.' (FM)
Access to information about ACP presented in a variety of ways (eg, written information; public advertising; normalising participation in ACP)	(F) Timely access to information on ACP, related documents and treatment options	'Information available to address these issues to be given out to family. More info about CPR, palliative care and other end-of-life treatment options before the patient is too ill.' (FM) 'Handout a routine form to normalise it that can be completed by patient and family and not in the presence of a doctor who I don't know.' (P) 'Our daughter's father-in-law died. We were aware of the living will that he had, then seeing the commercial on TV made us talk about it; we wanted to make plans to make it easier for our daughter to discuss with health care members.' (FM)
	(B) Lack of timely information on ACP, related documents or treatment options; information presented without opportunity for discussion	'I need to have this all written out; I am a visual person.' (P) 'We've been trying to figure out exactly which form and get the family together to discuss.' (P) 'The doctor instigated the discussion by giving the patient forms but family did not take part in the discussion.' (FM)
Access to a 'seamless' ACP system to provide continuity of care	(F) Clarity as to roles of different organisations and professionals and the necessary tools to assist person in sharing ACP across the system	'Would be good to carry a card in the wallet with GOC [Goals of Care] and ACP.' (P) 'If family doctor remains involved when patient is in hospital because he [sic] knows patient best and hospital doctors have to relearn patient's history which is frustrating to all. GP should be part of dialogue.' (FM)
	(B) Lack of clarity regarding what constitutes ACP and the roles of various organisations; lack of a protocol or system infrastructure for ACP	'Everything is arranged through the Coop Memorial Society [a funeral director]—no further action required.' (FM) 'No one at hospital admission wanted or knew what to do with the ACD [Advance care directive] that I brought in…' (P)

ACP, advance care planning; CPR, cardiopulmonary resuscitation;FM, family; GP, general practitioner; P, patient..

DISCUSSION

The use of a questionnaire to gather responses is both a strength and a limitation of this study. The major strength is that it has allowed us to capture a large number of responses from seriously ill, older people in the first few days of their hospital admission. This is a demographically important sector of our population who use a high percentage of healthcare resources[13] and who are historically under-represented in research.[14 15] The major limitation is that, as a semi-qualitative tool, we are reliant on the accuracy of what has been transcribed at the time of the interview and had no opportunity to ask clarifying or follow-up questions. The sampling strategy also limited participants linguistically, and therefore the sample is not as culturally diverse as the general population. Despite these limitations, the study validity is supported by the fact that the descriptive data, identified in the responses of the participants, are similar to other work on barriers and facilitators to ACP.[16–20] Organising the identified barriers and facilitators into a schematic, with the themes of person, access and the interaction, provides a framework that clinicians and healthcare system administrators can use to identify and test areas for improvement in ACP and medical decision making. We suggest some of these here (box 2).

Table 3 Elements of interaction between the doctor and the person or family member influencing engagement in ACP

Element of interaction	Facilitator (F) or barrier (B)	Illustrative quotes
Who initiates ACP	(F) ACP initiated by the doctor	'Dr. should initiate the conversation…needs good communication skills.' (P) 'They have to ask.' (FM)
	(B) The doctor doesn't ask or encourage the conversation	'Sometimes I tried to talk to my doctor about things and she ignores me.' (P) 'If they ask…otherwise we don't say anything.' (FM)
Amount of time for interaction between doctor and patient/family	(F) Allowing time for ACP or the decision-making process	'It isn't difficult if the MD's would be more available and take some time to talk to us.' (FM) 'Give more time to make the decision.' (FM)
	(B) Doctors who don't appear to make time for ACP	'They don't have the time to listen. If they start talking about it they say I have to go…another patient…makes it unpleasant.' (P) 'Dr. needs to spend more time…spend time and listen.' (FM) 'No time set aside for this, doctors don't ask me about my wishes…doctors focus on other problems during a clinic or office visit.' (P)
Location (both geographical and treatment context) of the interaction	(F) Information upfront before the crisis in a private place is most helpful	'Need more information at the outset…discussion in the ER was hard.' (P) 'Dr. needs to bring it up when the patient is well.' (P) 'Would want that conversation confidential, not in the hallway.' (FM)
	(B) Emergency room/health crisis makes conversations harder	'The way and time its asked is important. In a crisis like in ER, the patient does not understand the questions then.' (P) 'The ER is not the time to ask family's and patients. It is a very stressful time' (FM)
Relationship with doctor	(F) Relationship with doctor is central to feeling supported in the conversation	'My doctor is religious like me…we sometimes have a prayer together.' (P) 'I have a good relationship with my GP, can talk about anything.' (P)
	(B) Not having a good relationship negatively impacts the interaction	'I don't have faith in my doctor taking care of an older person… she is not interested in my problems. Doctors don't ask me about my wishes.' (P) 'Feels doctor sees him as a number and not a person.' (FM)
Qualities of communication	(F) The doctor communicates with compassion, honesty and respect	'Compassion, mutual sincerity, empathy and time needed.' (P) 'Gentle but honest.' (P) 'Openness, we are on a learning curve.' (FM) 'If they would actually tell my Mom about her life expectancy, prognosis and treatment.' (FM) 'I like a doctor I can talk to that will listen to another person's views, that will talk to me with good bedside manner, some don't feel comfortable talking about it.'(P)
	(B) A blunt, non-sensitive, closed approach with little time to respond	'Dr. needs to be more honest about the prognosis.' (P) 'Need more deep active listening rather than the one off approach.' (P) 'He was very blunt and I had to make a decision with little opportunity to discuss.' (FM)
Ease of comprehension of information provided by doctor	(F) Information is provided in a way that is easy to understand (B) Information is presented in a way that is difficult to understand	'More understanding, in words that are easy to understand.'(P) 'I want in plain words how long he has to live.' (FM) 'Doctors don't use layman terms and don't explain options—drawbacks and benefits of the options.' (FM) 'No clarity. They didn't explain it all. Every time I come in, it is the same thing. I have been in the hospital 3 times in the last year.' (P) 'The way that the doctor asked about CPR was very confusing. I was not sure what she was asking. She [patient] does not want any of that [CPR, breathing machines] so I need to make sure they understand.' (FM)

ACP, advance care planning; CPR, cardiopulmonary resuscitation;FM, family; GP, general practitioner; P, patient

Person

The findings reinforce the need for clinicians to assess readiness for participation and to adapt their approach to the person with whom ACP is being discussed. Fried et al have begun this work on tools to assess individual engagement in ACP with the lens of the transtheoretical model of behaviour change.[21] In examining the personal attitudes and beliefs expressed, it is interesting how frequently the theme of 'Not yet' was mentioned, especially given that we sampled patients at high risk of dying in the next 6 months. The 'Not yet' theme is common,[18–20] and this lack of planning for end of life has been linked to our society's taboos related to death and dying.[22] However, 'Not yet' is also related to the relevance of ACP to the person; Schickedanz[18] states, "Perceiving ACP as irrelevant was the most common barrier and was endorsed at every ACP step. Many participants perceived ACP as irrelevant, because they perceived themselves as 'too healthy', even though close to 70%

Box 2 Summary of suggestions for healthcare providers and systems

1. Helping a patient to acknowledge the personal relevance of ACP to him/her may improve readiness to participate in ACP.
2. Normalising ACP conversations through routine clinic visits with the family doctor/general practitioner or family meetings during hospitalisation may increase both the frequency of patient and family engagement in and their satisfaction with ACP.
3. Patients value sensitive, skilled communicators when discussing ACP. Education of healthcare providers (particularly doctors) should include a focus on developing communication skills for ACP.
4. Healthcare systems should ensure that the infrastructure is in place to support patients and healthcare providers engaging in ACP, for example, enabling access to appropriate documents and implementing processes to ensure that the output of prior ACP is available when patients are admitted to hospital.

reported having fair to poor health, and more than one-third reported having a previous admission to ICU." Relevance is amenable to change by helping persons to place ACP within the context of their own health/illness trajectory/prognosis and by encouraging all adults to perceive benefit in planning for unanticipated loss of capacity. Our data suggest that some people whose personal experience and beliefs support a willingness to participate may find that written or video information[23] will enable them to self-engage, while others with personal concerns may benefit from person-to-person emotional support that explores reasons to participate that align with their fears or personal barriers. Healthcare providers can also be encouraged to give realistic information to patients and families, overcoming a common barrier to ACP, which is their tendency to reassure and convey, 'That all is well'.[19]

Access factors

The importance of access to doctors was repeatedly stated and reinforces the need people have for an established primary care provider in the community and clarity as to the most responsible doctor while in hospital. A number of healthcare providers can participate in ACP interactions,[6 24 25] including nurses, social workers, spiritual care providers, as well as doctors, but how people perceive different healthcare professionals roles in ACP and how that impacts the interaction are yet to be fully established. Meanwhile, our results suggest that family doctors of older patients, particularly those with progressive life-threatening illness, should encourage patients to

include a family member or surrogate decision-maker in at least one routine visit to discuss prognosis and life-sustaining treatments. Similarly, when in hospital, our findings suggest that routinely offering a scheduled family meeting for patients and families with the attending doctor, to share prognosis and explore their wishes regarding life-sustaining treatments, might improve medical decision-making outcomes. Health systems wishing to promote this activity need to ensure access to quiet, private spaces in which to conduct this sensitive communication. These are not novel suggestions but they are ones that, at least in our own clinical experience, have been hard for healthcare systems and healthcare providers alike to prioritise among the competing pressures of bed occupancy, limited time and cost containment. Participants' comments, concerns and misinformation about the role of ACP documentation also illustrate the need for healthcare systems to organise infrastructure and improve public understanding of how to ensure patients' previously documented wishes can be accessed and honoured in every healthcare setting.[2]

The interaction

A prior, positive relationship with a doctor was valued by patients and families, but many respondents conveyed a willingness to discuss issues related to life-sustaining treatment if they were *asked to* do so by whichever doctor they encountered. The willingness of that doctor to initiate the ACP conversation and the quality of communication within that interaction appeared foremost in the patients' and families' assessment of facilitators. Doctors' reluctance to initiate ACP is a common barrier,[22] often related to their concerns that a person may lose hope if given an unfavourable picture of their future health status. It is therefore important for doctors to learn from this study that many chronically ill, older people and their family members are already thinking about future healthcare decisions and would be willing to engage in conversation if initiated. Of note, a similar population of Canadian, hospitalised, older patients and their families also rated trust in and honesty of their doctor as key elements in quality end-of-life care.[26] Disease-specific management guidelines are promoting ACP, with emphasis on communicating prognosis and treatment outcomes.[27 28] All of this reinforces the importance of teaching communication skills in undergraduate and graduate medicine and for healthcare policies and systems to support all healthcare providers in engaging in ACP.

Our schematic derived from qualitative data from the first cycle of the ACCEPT describes the barriers and facilitators perceived by patients and families. In doing so, we suggest targets for intervention by healthcare providers and healthcare system policymakers and administrators that have the potential for improving the quality and quantity of ACP.

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