

ACP Conversations with Chinese and South Asian Patients: Physicians' Perspectives of Barriers and Facilitating Factors



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<https://doi.org/10.5770/cgj.26.691>

ABSTRACT

Introduction/Objective

Advance Care Planning (ACP) discussions are infrequently conducted with physicians, even fewer among minorities. We explored physicians' experiences in engaging Chinese (CH) and South Asian (SA) patients in ACP conversations to understand initiation and participation patterns, topics covered, and barriers and facilitating factors.

Method

Twenty-two physicians with 15%+ SA patients aged 55+ and 19 with 15%+ CH patients aged 55+ were interviewed.

Results

SA- and CH-serving physicians described similar initiation patterns, cultural context, and need for standardized ACP routines. However, the SA-serving physicians described greater involvement of family members, while CH-serving physicians described more communication barriers and family members' desire to hide the diagnosis from patients.

Conclusion

Cultural taboos surrounding discussion around death and dying appear to influence CH older adults and families strongly. Lack of familiarity with ACP amongst the SA population accounts more for their limited engagement in ACP discussions.

Key words: advance care planning, ethnic minorities, barriers, facilitating factors, South Asian, Chinese, older adults

INTRODUCTION

Advance Care Planning (ACP) is defined as a communication process that supports people in understanding and sharing their personal values, life goals, and preferences related to future medical care. Adults at any age or stage of health are

encouraged to start an ACP conversation with their loved ones, future substitute decision-makers, or health-care providers.⁽¹⁾ ACP empowers older adults to plan for a future where they may no longer be able to make their own decisions.^(2,3) It can improve patients' experiences by aligning treatment with their preferences and avoiding unwanted and costly invasive treatments. ACP also reduces the burden and stress experienced by health-care providers who must make care decisions often with limited knowledge of patient preferences. In addition to discussing one's wishes and goals for medical care, ACP also includes completing one or more of the following documents: an Enduring Power of Attorney, a Representation Agreement, and/or an Advance Directive.⁽⁴⁾

Primary care physicians are the point of first and continuing contact for patients, often having a long-term relationship with them. This unique position allows them to monitor changes in their patient's health and functional status and, ideally, to identify an appropriate time to initiate the ACP process. Research supports primary care physicians' role in identifying individuals at risk of deteriorating health or pending death and as the front line for discussing ACP.⁽⁵⁾ However, ACP is not routine within primary care practices.⁽⁶⁾ Several studies reveal that people talk more about ACP with their family and friends than with their doctors or other health-care providers.⁽⁷⁾ A Canadian study of older patients in primary care settings⁽⁸⁾ reported that only 52.8% had spoken to someone about their treatment preferences in the event of illness and hospitalization, and that only 17.5% of these conversations were with a family doctor. Leaving physicians out of the ACP discussion may result in patients receiving non-desired care.⁽⁹⁾ The current literature also suggests that some physicians are reluctant to initiate a conversation about ACP since they may not feel comfortable discussing death with their patients or are afraid of taking away their hope.⁽¹⁰⁾

The concept of ACP originated in the USA and has been heavily influenced by Western cultural norms.⁽¹¹⁾ Although there is increasing interest in ACP, non-white racial or ethnic groups are less likely to engage in it or complete ACP

documents.⁽¹¹⁾ A systematic literature review⁽¹²⁾ identified that collectivistic cultural values and spirituality/religion influenced ACP engagement among racial and ethnic minorities in the USA. Another recent US study⁽¹³⁾ identified widespread clinician- and institution-level barriers to discussing ACP with certain racial and ethnic groups. These patients with limited health literacy and non-native English speakers may experience disparities in ACP completion and, consequently, inequitable end-of-life care.

Ethnic South Asian (SA) and Chinese (CH) now account for the first and second largest visible minority groups in Canada, making up 7.1% and 4.7% of Canada's population, respectively, according to the 2021 census.⁽¹⁴⁾ However, little is known about their preferences for end-of-life care. Culturally, they do not like to talk about death, and planning for one's death is considered uncomfortable and unnecessary. Usually, the extended family plays a significant role in patient care and makes all the end-of-life decisions, not the individual/patient.⁽¹⁵⁾ Many CH families object to telling the patient a "bad" diagnosis or prognosis, which may hinder the chance of advance care planning (ACP) discussion.⁽¹⁶⁾ Compared to the general population, Canadians with CH and SA ethnic origins have lower rates of ACP completion and a higher preference for aggressive medical care measures (e.g., resuscitation, feeding tubes, cardiopulmonary resuscitation). This difference may be due to difficulty in patient-physician communication, reduced access to palliative care services, or varying end-of-life perspectives and understanding. Patient-related barriers that stop ethnic minorities from discussing ACP and completing documents have been widely investigated, and lack of knowledge about ACP and cultural and religious norms, values, and preferences have been identified as crucial factors.^(11,17,18) On the other hand, a surprising result from a Canadian study⁽¹⁹⁾ showed higher rates of discussions with health-care professionals about end-of-life care preferences among individuals born outside Canada. This may be attributed to the fact that health-care professionals assume these patients have less information on ACP and are less likely to engage in it, so they overcome any reluctance they may have in initiating a discussion.

The relationship between ethnic minority patients and physicians is under-represented in the ACP literature. A systematic review of studies describing physician, patient, and health system barriers perceived by general practitioners⁽²⁰⁾ did not specifically explore clinicians' views on ACP conversations or if the topic was discussed, with a focus on ethnic minority patients. Further, the views of other types of physicians interacting with minority patients at the end of life also need to be explored. Assisting with ACP is not the sole purview of primary care providers; hospitalists also engage in ACP with a shorter and more intense timeline.

Also, research on using evidence-based ACP tools to engage patients in shared decision-making is at an early stage, and little is known about the accessibility and usage of these tools among physicians in health-care settings⁽²¹⁾ and, in particular, with ethnic minorities.

This study aimed to explore physicians' experiences in engaging CH and SA patients in ACP conversations. It aimed to understand initiation and participation patterns of the discussions, topics covered, barriers, and facilitating factors that physicians encounter when initiating or carrying out ACP discussions with CH and SA patients. We also wanted to investigate physician training in ACP facilitation, and the use of ACP tools with these groups to facilitate ACP discussions and improve patient knowledge and awareness of treatment choices. Specific research questions were:

- Do physicians adopt similar or different approaches when engaging in ACP discussions with CH compared to SA older adults?
- Do physicians identify similar or different barriers and facilitating factors when conducting ACP discussions with these two minorities?
- Do physicians serving the CH and SA populations have comparable ACP training and use tools to the same extent?

We speculated that there might be differences based on previous research conducted by others and our research team. This study is part of a larger national project entitled "Improving Advance Care Planning for Frail Elderly Canadians" (iCAN-ACP), funded by the Canadian Frailty Network.⁽²²⁾ Its objective is to increase uptake, impact, and access to ACP among older Canadians living with frailty across primary care, long-term care, and hospital sectors. A subset of the project is being conducted by The Diversity Access Team, headquartered at the Simon Fraser University Gerontology Research Centre. The Diversity Access Team aims to increase ACP participation among LGBT and ethnic minority older adults, particularly CH and SA groups, which, as indicated above, are Canada's largest visible minorities. Previous studies conducted by the team and others have found that discussions surrounding death and dying are taboo topics for many older CH adults and their families, which may explain the lack of ACP discussion with their physicians amongst that population. ACP may also conflict with the concept of filial piety, which is strongly embedded in Confucius theology. However, while intergenerational support is also central to SA culture, it is our perception that, as a concept, it carries less weight for SAs than filial piety does for CH individuals. Prior studies conducted by the team⁽²³⁾ have found a general lack of awareness of ACP and end-of-life options among SA older adults, which may account for their low engagement with physicians in ACP discussion to a greater extent than religion or culture taboos. We wanted to ascertain whether physicians serving these two groups would share our perceptions.

METHODS

Data for this study derives from interviews with Canadian primary care physicians and hospitalists with a practice comprising 15 per cent or more of SA or CH older adults (age 55+). A total of 41 interviews were conducted, 22 with physicians serving the SA population and 19 with those serving the CH

population. Data were collected in two phases; the first set of interviews (n=28) were conducted between Jan-Apr 2020, and the second (n=14) over May-Oct 2021. Various recruitment methods were utilized, the most successful of which was the snowball method, with previously interviewed physicians providing e-introductions to potential participants. Approval for the study was received from the Simon Fraser University Research Ethics Review Board (approval number 2019s0302).

The first set of study participants could choose to have their interview conducted in person, by telephone or by video-conference over Zoom. However, in person, interviews were precluded in the second set with the advent of the COVID-19 pandemic. Participants were asked to complete a questionnaire prior to the interviews designed to identify their socio-demographic characteristics, extent and type of ACP training, and experience with ACP tools.

Thematic analysis was conducted using a blended, mixed methods approach previously employed by the research team.^(23,24,25) This approach involved transcribing the recorded interviews verbatim and coding them using a detailed codebook developed by the research team. IBM SPSS version 22 (IBM SPSS Statistics, Armonk, NY) was implemented for quantitative analysis of the demographic data using Chi-Square and independent *t*-tests, with alpha = 0.05 considered the significance level.

RESULTS

Socio-demographic Characteristics of Study Participants

On average, the physicians interviewed about engaging in ACP discussions with SA patients had a practice comprising 28.5% SA older adults, and those interviewed about CH patients,

34.1% older CH adults. There were 11 PC physicians and 11 hospitalists in the SA-serving group, and 11 PC physicians and eight hospitalists in the CH-serving group (Table 1). More SA-serving physicians (36%) had received specialty training compared to CH-serving physicians (32%). Specialty training included geriatrics (SA:3, CH:4), laboratory and medicine policy (SA:1, CH:0), hematology (SA:1, CH:0), medical ethics (SA:1, CH:0), family medicine (SA:1, CH:0), rheumatology (SA:0, CH:1), and general internal medicine (SA:1, CH:1).

A majority of physicians in both groups were female (SA: 68%, CH: 68%). The SA serving group was older (mean age SA = 42.6; CH = 40.4). A greater proportion in the SA serving group was foreign-born (SA = 54.5%; CH = 52%), with individuals in one or both groups immigrating from India (SA:5, CH:1), Hong Kong (SA:2, CH:3), Taiwan (SA:2, CH:3), Pakistan (SA:2, CH:2), and China (SA:0, CH:3). Among those born outside of Canada, the SA group were more recent immigrants (58% immigrated to Canada after 1989 compared with 50% of CH-serving physicians). Regarding ethnic similarity with the groups they served, 64% of the SA-serving physicians identified their ethnocultural background as SA; 58% of the CH-serving physicians identified their ethnocultural background as CH. Religions practiced by the participants included Roman Catholic (SA:3, CH:3), Hindu (SA:4, CH:1), Islam (SA:3, CH:1), Sikh (SA:4, CH:3), Protestant (SA:1, CH:2), Buddhist (SA:2, CH:2), United Church (SA:0, CH:1), Jainism (SA:1, CH:0), and Sanatan Dharma (SA:1, CH:0); a subset reported having no religion (SA:3, CH:5).

As shown in Table 1, 63% of the SA-serving physicians were able to communicate verbally with their patients in Hindi or Punjabi; 73% of the CH-serving physicians spoke Mandarin or Cantonese. Fewer were able to read and write in those languages.

TABLE 1.
Socio-demographic characteristics of interviewed physicians

Variable		SA Interviews (n=22)	CH Interviews (n=19)	P Values
Practise Type	Primary Care	11	11	.163
	Hospitalist	11	8	
Age	Mean (SD)	42.55 (10.89)	40.42 (9.44)	.511
	Range	30 – 74	30-58	
Sex at Birth	Male	7	6	.987
	Female	15	13	
Country of Birth	Canada	10	7	.577
	Other	12	12	
Year arrived in Canada		(n=12)	(n=12)	.682
	Before 1990	5	6	
	1990 or after	7	6	
Ethnic cultural background	South-Asian	13	5	.056
	Chinese	5	11	
	Other	4	3	
Additional languages reads & writes	Hindi/ Punjabi	6	2	.067
	Traditional/Simplified Chinese	3	5	
	Other	8	1	

Training in ACP and ACP Tools Used

While a majority of both groups had some ACP training, more of the physicians working with the CH population (79%) had completed ACP training than those serving the SA population (64%). Of the 14 physicians catering to the SA population, two had completed training in the past six months and 11 more than a year earlier. For the majority, training was in-service (n=6) or through a course (n=5), and for the remainder, through workshops and reading (n=3) or as part of their residency or specialty training. Likewise, 13 of the 15 CH-serving physicians that had completed the training had done so more than a year earlier, most receiving it through a course (n=10) or via in-service (n=5) and, for the remainder, through seminars, workshops, and practice (see Table 2).

A majority in both groups reported using tools to facilitate discussion (SA=59%; CH=63%). Of the four tools inquired about, the *Serious Illness Conversation Guide* was most commonly used by both groups (SA=10; CH=9), followed by *My Voice: Expressing My Wishes for Future Health Care Treatment* (SA=6; CH=6), *Conversation Starter Kit* (SA=4; CH=3), and *My Wishes, My Care* (SA=1; CH=2).

Similarities

The SA-serving physicians' data closely resembles that of the CH-serving physicians with the same nine themes emerging: Fostering ACP Discussions, Form/Content of ACP Discussion, Tools and Resources, Physician Evaluation of ACP Discussion, Culture, Family Dynamics, COVID-19, Comparisons, and Suggestions.

Most physicians stated that it was usually they who initiated the discussion. As one CH serving physician noted, where a family member initiated the conversation, "it ... [was] their kids who speak English, but this [was] very rare." Physicians usually initiate conversation if there is a change in the patient's health, as "every single patient that comes into the hospital needs to have a conversation about ACP status" or when discussing billing and paperwork.

Different forms and methods of ACP were mentioned by both the SA- and CH-serving physicians; in particular,

they stressed that conversations needed to take place over multiple office or hospital visits. Both groups reported taking a patient-centred approach when engaging in discussion and gaining "an understanding of what [the patient's] wishes are" while focusing on understanding the "kind of quality of life [they] wish to have as [they] age." Physicians reported that they usually directed the conversation with some "try[ing] to give [the patient] the most informed decision based on the medical advice that [they] have" and others "... [identifying] the substitute decision maker, and then try[ing] to document it ... for every patient."

Concerning family involvement, a majority of physicians serving both the SA and CH population identified that "SA and the CH population have very similar cultures in terms of ... very involved families, wanting the best... it's hard for them to accept that ... end-of-life care planning is ... the next step." The interviewed physicians also stated that "[SA and CH] cultural groups [are] very present with their loved ones in hospital and ... want to be the decision maker for their loved one even if their loved one can make their own decisions for the most part."

Both SA and CH serving physicians discussed a need for a standardized ACP routine, with one stating that "at the top of [patient's] chart ... should be an ACP piece of paper or [EMR] note. [Dr] should be able to click the EMR and see the ACP status...that usually guides so much of clinical decision-making." A few also discussed an increased need for support and resources from the health authority/ministry because "for all the doctors to have sufficient time to go over [ACP], it needs to be built into the funding structure." They identified a need to provide ACP education amongst the SA and CH populations if more discussions with physicians were to occur.

Differences

More SA-serving than CH-serving physicians reported family members' involvement and that their patients discussed end-of-life issues with non-family members when making decisions. However, when discussing family involvement,

TABLE 2.
Physicians ACP training and tool use

Variable		SA Interviews (n=22)	CH Interviews (n=19)	P Values
ACP training received	Yes	14	15	.283
	No	8	4	
When was training completed		(n=13)	(n=15)	.506
	Past six months	0	1	
	Less than a year ago	2	1	
	More than a year ago	11	13	
Training format		(n=13)	(n=15)	.900
	In-service/ Course	10	15	
	Other	3	5	
ACP tools used	Yes	13	12	.790
	No	9	7	

physicians identified that both CH and SA families have significant involvement in patient care, and the family's perspectives impacted their care. Also, physicians serving the SA and those serving the CH populations discussed the fear experienced by the family in engaging in ACP discussion; however, the reasons behind the fear differed for the two groups. The SA families feared that "if they [initiate ACP], it might be taken the wrong way [i.e., the children are trying to escape their responsibilities]." In contrast, the CH "don't want [patient] to know all the information because they don't want them to lose hope or be scared or be frightened."

A recurring theme identified amongst the CH-serving physicians was that CH families felt a need to protect their elders by limiting the patient's knowledge of their diagnosis. As one physician stated, "[I] think it's the CH group that's doing [charade of silence] a lot [and] ... [I] haven't seen [this] in SA group."

Physicians identified that there were more communication barriers amongst the CH population compared to the SA population; as one noted, "a lot of times in the CH population, the families also don't speak English ... [and] SAs, [do] speak English. So [physician] can talk to them directly." Likewise, while some physicians serving the SA and some serving the CH population reported using tools and identified barriers associated with tool use, more SA-serving physicians evaluated the available tools and described the advantages of tool use.

DISCUSSION

Arnett *et al.* found that many health-care providers identified ACP as the physicians' responsibility.⁽²⁶⁾ Physicians from our study mirrored these results, as they stated that the few ACP discussions conducted with our two ethnic minorities of interest were mainly initiated by themselves. Furthermore, Yarnell *et al.* found that compared to the general population, the SA and CH populations were more likely to die in intensive care and receive aggressive end-of-life care.⁽²⁷⁾ These authors identified several possible explanations for the increased likelihood of extreme measures, including cultural differences, decreased ACP literacy, and family/patient preference, all discussed by our physicians.

However, even though physicians stated that the SA and CH population do not regularly engage in ACP discussion, our belief, echoed by the SA-serving interviewed physicians, is that the underlying reasons differ for the two groups. For the SA population, the primary reason is the lack of knowledge as "the concept of ACP is not common ... [for the SA] ethnic minority community. So, often it can be the first time the subject has been broached." Therefore, the physician must first educate the SA patient and their family about the concept of ACP discussion and then engage in discussion.

For the CH community, the physicians identified that "... [death] is such a taboo [topic] that [they] don't talk about it ... [because] that will break the relationship with [their] patients." They further stated that "[ACP discussion] is still

something culturally that children find difficult to talk to their parents about ... there is still some cultural sensitivities around it," and they "don't know if the narrative of allowing a natural death is something that is culturally understood." Thus, physicians must take a patient-centred approach and be mindful of cultural limitations. Consequently, the approach to increase engagement must be tailored to cater to each group.

Furthermore, more SA- than CH-serving physicians reported family members' involvement and that their patients discussed end-of-life issues with non-family when making decisions. SA-serving physicians also identified that children dominate the patient's rights and make decisions in place of the patient, whereas this was not a common comment about the CH population. This may be because SAs have a much more extensive social network than the CH due to the one-child policy in China in the past.

Our findings of physicians' perceived barriers differ from those identified by Howard *et al.* in their study of mainstream Canadian physicians, which tend to focus on administrative issues.⁽²⁸⁾ For example, they determined lack of time, difficulty transferring patients' ACP documents electronically, and decreased patient interaction due to transfer of care as the most significant barriers to engaging in ACP discussion with their patients. In our study, physicians serving both SA and CH populations focused more on patient-related barriers. These included patient lack of awareness and knowledge of ACP, increased tendency to deflect their decision-making onto physicians, cultural barriers, and communication barriers as the major barriers influencing ACP engagement. While in similarity to Howard *et al.*, some SA-serving physicians identified a lack of time, they were more vocal in drawing attention to physicians' lack of tool knowledge and children dominating the patient's rights as barriers to engaging in ACP discussion.⁽²⁸⁾ The CH-serving physicians identified death as a taboo and a culturally sensitive topic as added barriers.

More SA-serving physicians discussed the advantages of ACP tools compared to CH-serving physicians. The less frequent identification of advantages of tool use amongst the CH-serving physicians could, in part, be due to language barriers which are more prevalent in the CH community, where fewer spoke English. Statistics Canada reported that 35% of Canadians whose mother tongue was Cantonese or Mandarin could not speak English or French, compared to 12% of the Punjabi population.⁽²⁹⁾

CONCLUSION

The SA and CH populations should be considered separately when devising approaches to engage the two minorities in ACP discussion and when developing ACP tools and resources, as they have different barriers and cultural values. Physicians recommend that ACP be a standard part of routine patient care, but tailored to incorporate each population's specific values and norms. Furthermore, more physicians serving the SA and CH populations should be formally trained in ACP,

including how best to raise and navigate such discussions with the two populations. They should also be educated about available tools and resources, particularly those specifically adapted for use with the SA and CH populations where they exist. Adaptation involves more than simple translation of tools developed for a mainstream white English-speaking population. Our study also highlights the importance of incorporating specific values and norms of each population to provide a more comfortable ACP experience. We would argue against “one size fits all Asians” approaches on the grounds that they are insufficiently nuanced to address older adults’ and their families’ concerns and sensitivities.

ACKNOWLEDGEMENTS

This study is part of a larger project (iCAN-ACP) funded by a grant from the Canadian Frailty Network (formerly Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) program.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal*'s policy on conflicts of interest disclosure and declare there were no financial, commercial, professional, or legal conflicts of interest related to this work.

FUNDING

This work was supported by the Canadian Frailty Network [TG2015-03 Transformative Grant].

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