

Original Article

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Barriers to advance care planning among patients with advanced serious illnesses: A national survey of health-care professionals in Singapore

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Abstract

Objectives. To assess the barriers that health-care professionals (HCPs) face in having advance care planning (ACP) conversations with patients suffering from advanced serious illnesses and to provide care consistent with patients' documented preferences.

Methods. We conducted a national survey of HCPs trained in facilitating ACP conversations in Singapore between June and July 2021. HCPs responded to hypothetical vignettes about a patient with an advanced serious illness and rated the importance of barriers (HCP-, patient-, and caregiver-related) in (i) conducting and documenting ACP conversations and (ii) providing care consistent with documented preferences.

Results. Nine hundred eleven HCPs trained in facilitating ACP conversations responded to the survey; 57% of them had not facilitated any in the last 1 year. HCP factors were reported as the topmost barriers to facilitating ACP. These included lack of allocated time to have ACP conversations and ACP facilitation being time-consuming. Patient's refusal to engage in ACP conversations and family experiencing difficulty in accepting patient's poor prognosis were the topmost patient- and caregiver-related factors. Non-physician HCPs were more likely than physicians to report being fearful of upsetting the patient/family and lack of confidence in facilitating ACP conversations. About 70% of the physicians perceived caregiver factors (surrogate wanting a different course of treatment and family caregivers being conflicted about patients' care) as barriers to providing care consistent with preferences.

Significance of results. Study findings suggest that ACP conversations be simplified, ACP training framework be improved, awareness regarding ACP among patients, caregivers, and general public be increased, and ACP be made widely accessible.

Introduction

Many patients dying with advanced serious illnesses receive end-of-life care inconsistent with their goals and preferences (Covinsky et al. 2000; Dy 2016; Khandelwal et al. 2017). Although most wish to die at home and be free of any suffering (Heyland et al. 2017; Lee et al. 2020; Malhotra et al. 2015, 2017; Mandel et al. 2017; Tang 2003), many are unable to do so (Mandel et al. 2017; O'Brien and Jack 2010). Advance care planning (ACP) is an intervention that aims to facilitate end-of-life care consistent with an individual's preferences (Brinkman-Stoppelenburg et al. 2014). It is defined as a process of "enabling individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care professionals (HCPs), and to record and review these preferences if appropriate" (Rietjens et al. 2017).

Despite the promise, several trials have shown that ACP programs may not facilitate end-of-life care consistent with patients' preferences (Bernacki et al. 2019; Johnson et al. 2018; Kirchhoff et al. 2012; Malhotra et al. 2020; Schubart et al. 2019; Tang et al. 2019). As a result, some have now questioned the purpose of ACP (Morrison et al. 2021; Sean Morrison, 2020). Although the idea of ACP seems straightforward in theory, its implementation is complex (Flo et al. 2016; Vanderhaeghen et al. 2019). Past literature has explored the barriers patients, caregivers, physicians, and HCPs face, which prevent ACP conversations. However, most of these studies were conducted in the context of specific disease groups, HCP groups, or health-care settings, thus limiting their generalizability to the entire health-care system (Ali et al. 2021; Beck et al. 2017b; Blackwood et al. 2019; Cheung et al. 2020; Fanta and Tyler 2017; Fulmer et al. 2018; Howard et al. 2018; Martina et al. 2021; Reich et al. 2022; Shepherd et al. 2018; Vanderhaeghen et al. 2019; Yee et al. 2011). Less is known about the complexity of implementing a nationwide ACP program in multiple settings within the health-care system. Further, Singapore's national ACP

program is one of the oldest in Asia (Cheng et al. 2020), and its experience may benefit other countries in implementing their own ACP programs.

Singapore's national ACP program, "Living Matters," is modeled after the Respecting Choice Program (Gunderson Health System n.d.; Malhotra and Ramakrishnan 2022). It was first launched in 2011 and implemented in the inpatient settings across public hospitals in Singapore. Subsequently, its second phase, launched in 2017, expanded the program to outpatient settings in public hospitals, public primary care clinics, and nursing homes. To better understand the complexities and barriers of effective ACP program implementation by a diverse group of HCPs in Singapore, we carried out a survey of HCPs formally trained in facilitating ACP conversations. Anecdotally, many HCPs, even after training, do not facilitate ACP conversations with patients for unknown reasons. Therefore, our first aim was to assess barriers that HCPs face in facilitating ACP conversations with patients suffering from advanced serious illnesses and in providing end-of-life care consistent with patients' documented preferences. Based on previous literature (Ali et al. 2021; Cheung et al. 2020; Martina et al. 2021), we hypothesized that patient- and caregiver-related factors would be perceived to be more important barriers to ACP conversations than HCP factors. Our second aim was to identify which occupational subgroups within HCPs were less likely to have ACP conversations with patients. Based on prior literature (Dixon and Knapp 2018), we hypothesized that physicians would be less likely to have ACP conversations with their patients compared to other HCPs.

Methods

Study setting and participants

We conducted a cross-sectional web-based survey with HCPs in Singapore. The survey was open for 4 weeks (14 June and 12 July 2021) to the participants. During this time, an email reminder was sent to the participants at least once per week to complete the survey. The survey was the second phase of a sequential mixed-methods study. Phase 1 of the study consisted of focus group discussions with HCPs across Singapore.

All Singapore-based HCPs who had received a formal 1-day ACP facilitation training were eligible to participate, regardless of health-care practice setting. All HCPs were employed in one of the public institutions in Singapore at the time of the survey. HCPs that had not completed the standardized training in ACP facilitation were excluded from the study. Email addresses of eligible HCPs were obtained through a database of professionals trained in facilitating ACP. HCPs provided online consent and responded to the web survey. No identifying information was recorded.

The study was approved by the institutional ethics review board at the National University of Singapore.

Questionnaire development

The survey questionnaire was developed based on a review of literature and preliminary results from 22 focus group discussions conducted with 107 HCPs in 25 organizations (Malhotra and Ramakrishnan 2022). Following that, the content validity of the questionnaire was assessed by study team members and policy experts overseeing the implementation of ACP program in Singapore. Its face validity was then assessed during pretesting with 6 respondents. Survey questionnaire was revised based on feedback

from experts and pretesting results. As the intent of the survey questionnaire was not to combine individual items to form a scale or a score, we did not assess the questionnaire's construct validity and internal consistency reliability.

The questionnaire elicited information on HCP demographics including their age, gender, professional characteristics including clinical role, number of years in current role, years since training in ACP facilitation, number of ACP conversations facilitated in the last 1 year, and frequency of seeing patients at their end of life and whether they had completed their own ACP.

HCPs were then presented with 2 vignettes describing hypothetical patient scenarios. The first vignette was administered to all HCPs trained in facilitating ACP discussions. It described a hypothetical elderly patient with an advanced serious illness, with an uncertain prognosis, and who had never had an ACP conversation. HCPs were asked to reflect on their last 1 year and answer how likely they were to have an ACP discussion with such a patient. Response options ranged from 1 to 3 (1, not likely; 2, somewhat likely; and 3, very likely) (Supplementary Figure S1). Following this vignette, HCPs were asked to rate the importance of 19 barriers to facilitating and documenting ACP conversations for such a patient. HCPs rated each barrier on a 5-point Likert scale (almost always, to a considerable degree, occasionally, seldom, and never) and ranked their 3 topmost barriers.

The second vignette was administered only to physicians trained in facilitating ACP conversations. It described the same hypothetical patient now hospitalized with an acute respiratory distress and unable to express his/her wishes. Patient had an ACP documented, indicating a preference for comfort care and no cardiopulmonary resuscitation. Without aggressive treatments, the patient was unlikely to survive. Physicians were asked to reflect on their last 1 year and answer how likely they would be to follow or execute hypothetical patient's preferences as recorded in his/her ACP document (Supplementary Figure S2). Following this vignette, physicians were asked to rate the importance of 8 barriers for providing care consistent with preferences recorded in the ACP document. Physicians rated each barrier on a 5-point Likert scale (almost always, to a considerable degree, occasionally, seldom, and never) and ranked their 3 topmost barriers.

Statistical analysis

We described HCPs' demographic and clinical characteristics, and the average number of ACP conversations facilitated by them.

We then categorized HCPs' perceived barriers as HCP-related, patient-related, and caregiver-related. We reverse-coded each barrier and calculated an average score (mean [SD]) for each (range: 1–5), with a higher score indicating greater importance for that barrier. For barriers related to facilitating ACP conversations and documenting them, we stratified scores by clinical role (physician versus others) and assessed statistically significant differences between the 2 groups using the Mann–Whitney test. We also stratified HCPs' top-ranked barriers by their clinical role (physician versus others) and assessed statistically significant differences between the 2 groups using Chi-square test. Lastly, we reported HCPs' (physicians') top-ranked barriers related to respecting patients' preferences as recorded in their ACP document.

Using a logistic regression model, we assessed which subgroup of HCPs were more likely to facilitate an ACP conversation in the last 1 year. Main independent variable was HCPs' clinical role (physician versus others). We controlled the model for other HCP characteristics – whether they had completed their own ACP

Table 1. Sample characteristics, $n = 911$

	<i>N (%)</i>
Age, mean (SD), $n = 904$	41.2 (10.1)
Gender, $n (%)$	
Female	698 (76.6)
Male	208 (22.8)
No response	5 (0.005)
Profession, $n (%)$	
Physician	189 (20.7)
Nurse	382 (41.9)
Medical social worker	159 (17.4)
Others ^a	181 (19.9)
No. of years in this role, $n (%)$	
<1 year	35 (3.8)
1–5 years	267 (29.3)
6–10 years	222 (24.4)
11–15 years	144 (15.8)
>15 years	243 (26.7)
Place of practice, $n (%)$	
Hospital	395 (43.4)
Primary care clinic	36 (3.9)
Nursing home	217 (23.8)
Hospice/Home care/Community center/community hospitals	125 (13.7)
Others ^b	61 (6.7)
No response	77 (8.4)
Number of ACP facilitated in the last 1 year, $n (%)$	
None	392 (43.0)
One or more	518 (56.9)
No response	1 (0.1)
Frequency of encountering patients at their end of life in routine clinical practice, $n (%)$	
Everyday	184 (20.2)
At least once a week	135 (14.8)
At least once a month	206 (22.6)
Rarely/ never	203 (22.3)
No response	183 (20.1)
Completed ACP for oneself, $n (%)$	
Yes	168 (18.4)
No	742 (81.4)
No response	1 (0.1)

^aIncluded allied health professionals, volunteers, care coordinators, general ACP facilitators, physical therapists, social work counselors, community social workers, and administrative professionals.

^bIncluded not-for-profit health organizations, social service agencies, and national and specialist medical centers.

Table 2. Responses to hypothetical vignettes

<i>Vignette 1: Conducting an ACP conversation with a hypothetical elderly patient and documenting it, $n = 911$</i>	
Not likely	123 (13.5)
Somewhat likely	330 (36.2)
Very likely	458 (50.3)
Total	911 (100.0)
<i>Vignette 2: Following/executing hypothetical elderly patient's preferences as recorded in ACP document, $n = 189$</i>	
Not likely	2 (1.1)
Somewhat likely	37 (19.6)
Very likely	150 (79.4)
Total	189 (100.0)

(yes versus no) and frequency of seeing patients at their end of life (daily, at least once a week, at least once a month, rarely, or never). Using separate logistic regression models, we also assessed the association between each perceived barrier to ACP facilitation (independent variable) and whether or not the HCP had facilitated an ACP conversation in the last 1 year (outcome variable).

All analyses were performed using Stata version 16.1.

Results

The survey was emailed to 2,628 HCPs, 1,675 responded, and 963 (36.6%) had complete responses. Of these, 911 HCPs who had received training in facilitating ACP conversations constituted the analytic sample (Supplementary Figure S3).

Table 1 shows the sample characteristics. Average age (mean [SD]) of the HCPs was 41 (10.2) years, and over three-quarter of the HCPs were females (77%). Nearly one-fifth of the HCPs were physicians (21%) and 42% were nurses. Forty-three percent of the HCPs were practicing at a hospital. Majority (81%) had not completed ACP for themselves. Notably, despite being trained in ACP facilitation, 43% had not facilitated any ACP conversation during the last 1 year. Among these respondents, 15% were physicians and 85% were non-physician HCPs (p -value <0.01) (Supplementary Table S1).

In response to the first vignette, only half of the HCPs (50.3%) reported that they were “very likely” to facilitate an ACP conversation with the hypothetical elderly patient and to document the conversation (Table 2).

Contrary to our hypothesis, HCP factors were perceived as the most important barriers to conducting and documenting ACP (Figure 1). Specifically, HCPs perceived conducting and documenting ACP as being time-consuming and reported lack of protected time for conducting ACP conversations. Physicians were more likely than other HCPs to report conducting and documenting ACP as time-consuming, absence of protected time to conduct ACP, and lack of recognition for their ACP work as barriers to having ACP conversations. HCPs being fearful of upsetting the patient/family, their lack of confidence in conducting ACP conversations, lack of knowledge about disease, lack of job clarity in terms of ACP, and not perceiving ACP were to be rated as least important barriers to conducting ACP; these barriers were rated as being more important by non-physicians compared to physicians. We did not find any difference between physicians and other

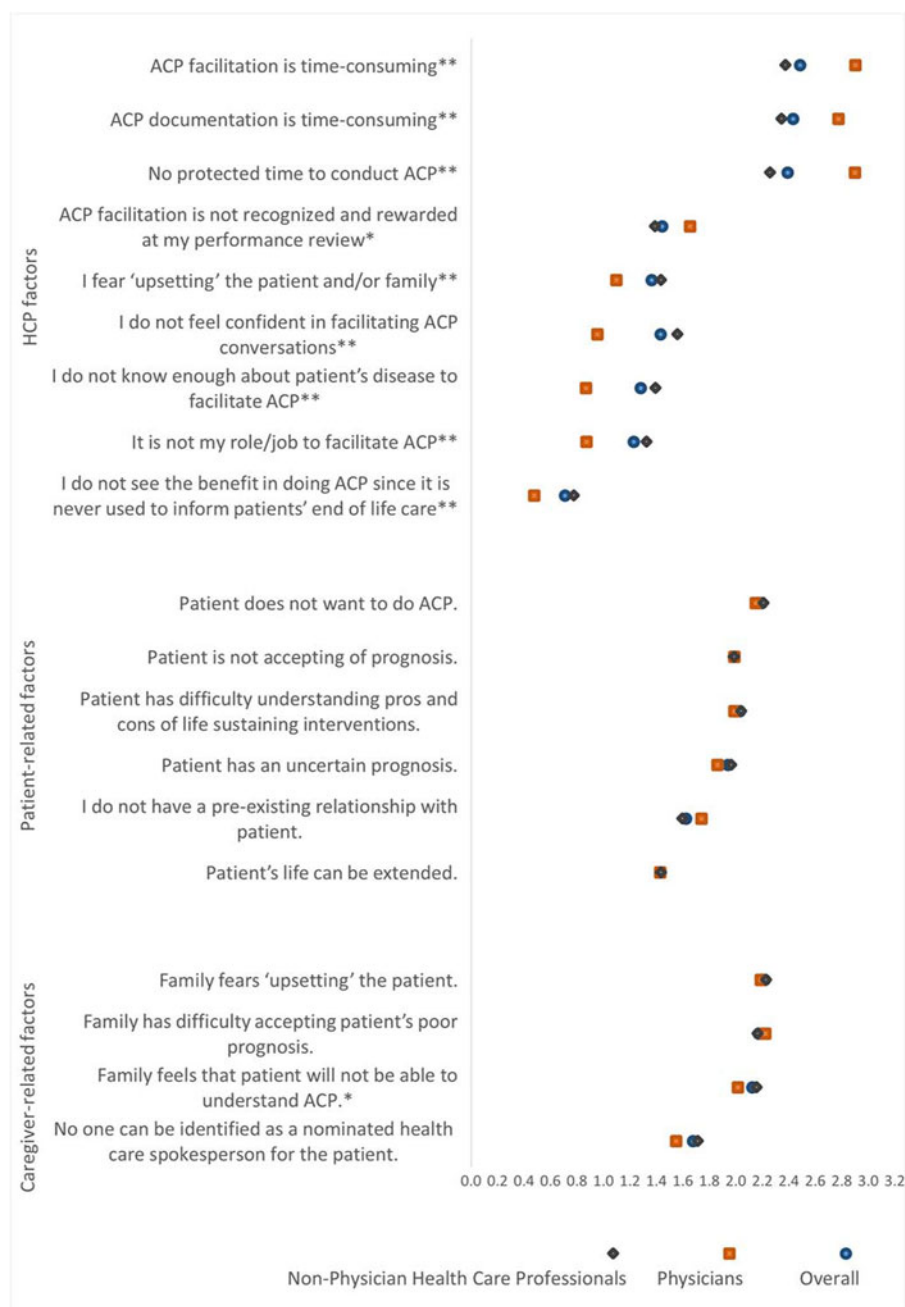


Fig. 1. Mean score for each barrier to conducting and documenting ACP conversations, $n = 911$.

** p -value < 0.01 and * p -value < 0.05

HCPs in terms of patient- and caregiver-related factors, except that physicians were less likely than other HCPs to report that family felt patient would be unable to understand ACP.

Among patient- and caregiver-related factors, patient's refusal to do ACP and family's difficulty in accepting patient's poor prognosis were listed as top-ranked barriers, respectively (Figure 2).

In response to the second vignette administered only to physicians, more than three-quarter reported they were "very likely" to follow hypothetical patient's preferences as recorded in their ACP document (Table 2). About 70% of the physicians perceived caregiver factors (surrogate wanting a different course of treatment compared to what was documented in the ACP document and family caregivers being conflicted about patients' care) as barriers for

providing end-of-life care consistent with documented preferences (Figure 3).

Contrary to the hypothesis, physicians were more likely (OR: 1.75; 95% CI: 1.20–2.56) to have ACP conversations with their patients compared to other HCPs. Furthermore, HCPs who had completed ACP for themselves (versus not completed) (2.29 [1.57, 3.35]) and those who frequently saw patients who were at their end of life (versus rarely/never saw) (everyday: 4.50 [2.88, 7.01]; at least once a week: 2.26 [1.41, 3.62]; at least once a month: 3.75 [2.47, 5.68]) were more likely to facilitate an ACP conversation in the past 1 year (Table 3).

HCPs who considered HCP and caregiver factors as perceived barriers to ACP facilitation were less likely to facilitate any ACP

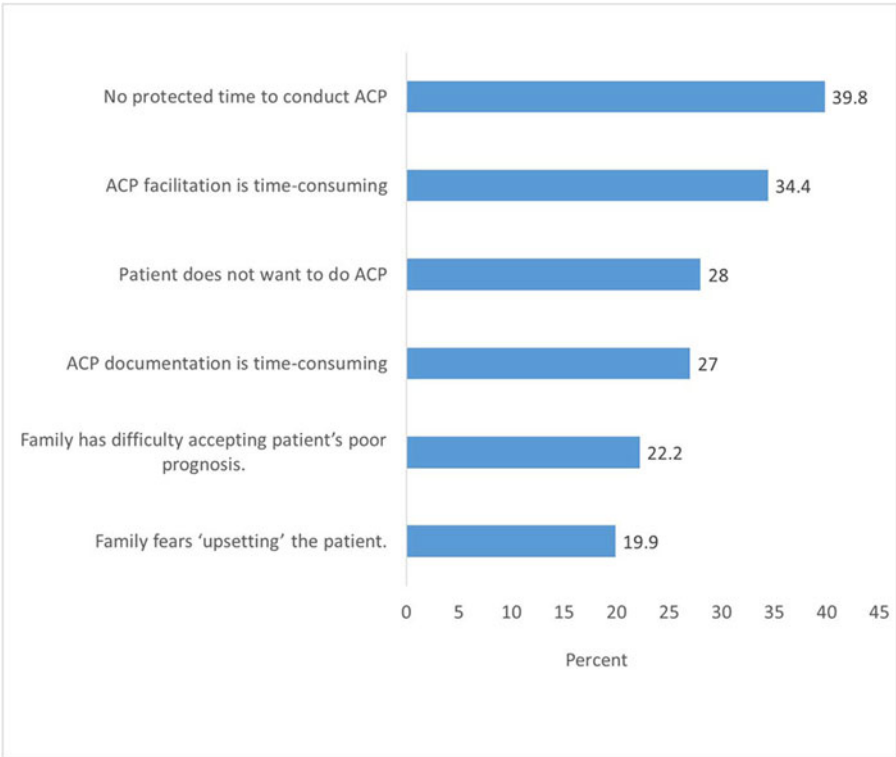


Fig. 2. Ranking of barriers to conducting and documenting ACP conversations, *n* = 911.

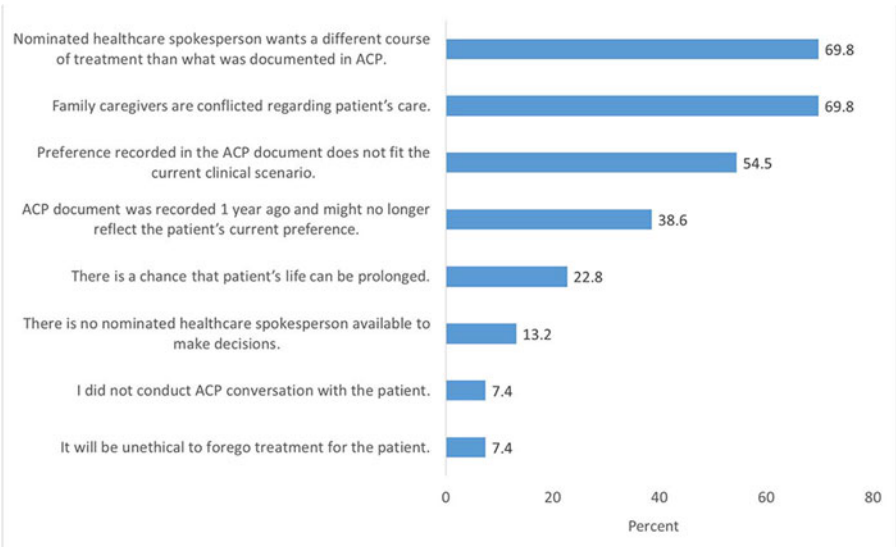


Fig. 3. Ranking of barriers to providing end-of-life care consistent with patient's documented preferences, *n* = 189.

conversations during the last 1 year in their actual practice. Among patient-related factors, HCPs who perceived patients' life could be extended' were less likely to facilitate ACP discussions in their actual practice during the last 1 year (Supplementary Table S2).

Discussion

In this national survey of HCPs trained to facilitate ACP conversations, we found that more than half had not facilitated any ACP conversations in the last year. We also found that HCP factors were

the topmost barrier for them to facilitate ACP conversations with patients with advanced serious illnesses. These included lack of protected time to have ACP conversations and ACP documentation being a time-consuming process. These factors posed a greater barrier for physicians compared to other HCPs.

The results are in contrast with a previous study that highlighted patient and caregiver factors to be the most important barriers to ACP conversations than HCP factors (You et al. 2015). Several other studies have, however, highlighted HCPs' lack of time as a key barrier for ACP conversations (Beck et al. 2017a;

Table 3. Association between actual number of ACP conversations in the past 1 year and characteristics of health-care professionals ($n = 909$)

	Odds ratio (95% CI)
Profession (ref: others)	
Physician	1.75 (1.20, 2.56)***
Completed ACP for oneself (ref: No)	
Yes	2.29 (1.57, 3.35)***
Frequency of seeing patients at their end of life (ref: rarely/never)	
Everyday	4.50 (2.88, 7.01)***
At least once a week	2.26 (1.41, 3.62)***
At least once a month	3.75 (2.47, 5.68)***
No response	2.28 (1.50, 3.47)***

*** p -value < 0.01.

Howard et al. 2018; Jezewski and Feng 2007; Sellars et al. 2015; Zhou et al. 2010). In Singapore, currently ACP conversations require one or more sessions, with each session lasting for at least an hour (Malhotra and Ramakrishnan 2022). Subsequently, ACP facilitators spend considerable time documenting the conversation, procuring signatures from patients, surrogates, and physicians, and uploading the documentation on an electronic platform (Malhotra and Ramakrishnan 2022). As a result, ACP conversations rarely take place during routine outpatient consultations. To address these barriers, simplification of ACP conversations and documentation process and allocating dedicated time within HCP's busy schedule would be required to make these conversations less time-consuming and efficient.

Results from our study also suggest that despite receiving the standardized training, many non-physician HCPs were fearful of upsetting the patient/family indicating their worry about lack of patients' readiness in having ACP conversations and of taking away patients' hope. Similar findings have previously been shown in Asian countries (Martina et al. 2021). Studies have also highlighted that Asian patients lack readiness in engaging with ACP conversations (Jia et al. 2022). Additionally, non-physician HCPs reported lack of confidence and knowledge to facilitate ACP conversations. Others have also highlighted these barriers (Howard et al. 2018; Jezewski and Feng 2007). This could be due to their limited experience in communicating with patients and their families compared to physicians and their lack of disease-specific knowledge (Fulmer et al. 2018; Owen et al. 2022). Our findings suggest that to allow HCPs to gain more disease-specific knowledge, gain greater confidence in facilitating ACP conversations, and be less fearful of upsetting patients/families, the current 1-day ACP training framework needs to be reviewed and strengthened (Malhotra and Ramakrishnan 2022).

We found that patient's refusal to do ACP was the top-rated patient-related barrier to having ACP conversations. It is thus important to raise awareness regarding ACP and its potential benefits. Future research can also seek to understand what motivates and enables patients to have ACP conversations. Increasing access to ACP and simplifying ACP conversations can also make them less fearful for patients.

It was encouraging that about 80% of the physicians surveyed were "very likely" to follow/execute the hypothetical patient's documented preferences. However, 70% perceived

caregiver-related factors (surrogate wanting a different course of treatment compared to what was documented in the ACP document and family caregivers being conflicted about patients' care) as barriers to providing care consistent with documented preferences. As patients' medical condition changes, involving caregivers in regular and ongoing ACP conversations can help resolve conflicts in values and treatment preferences between patients and caregivers, while allowing caregivers to have a better understanding and preparedness of patients' prognosis. This might increase the likelihood of caregivers making end-of-life decisions consistent with patients' documented preferences.

Previous studies support the use of an integrative approach, targeting the interests of all stakeholders including patients, caregivers, HCPs, and general public, to optimize ACP delivery by addressing the barriers to ACP conversations for all stakeholders (Fothergill et al. 2022; Park et al. 2019). Our findings further suggest that ACP conversation and documentation process be simplified and ACP be made more available and accessible to patients through multiple channels, for example, tele-ACP and web-ACP. Further, these conversations need to be repeated over a period of time. HCPs, especially physicians, may require dedicated time within their schedules to have ACP conversations. The existing training framework needs to be strengthened to instill greater confidence and disease-specific knowledge among HCPs, especially non-physician HCPs. Lastly, awareness about ACP needs to be improved within general public, patients, and their caregivers.

Our study has several strengths. It is a large national survey involving a diverse group of HCPs from multiple settings across the health-care system including hospitals, primary care clinics, nursing home, hospice, and home care settings. The survey questionnaire was designed based on responses from focus group discussions conducted by our team. The study also has limitations. First, there is a potential for response bias, with those responding to this survey having different perspectives than those who did not respond to this survey. Second, our sample comprised a high proportion of females and nurses and a lower proportion of providers from primary care settings, thus, limiting the representativeness of the sample responses to the wider population of HCPs trained in ACP facilitation. Third, because the survey was anonymized, the potential for respondents to complete the survey more than once cannot be completely ruled out. However, we estimate the potential for this to be low given the length of the survey and the lack of any financial incentive to complete the survey. Further, we monitored the response rate by each organization to assess any unusually high response rate within any organization; none was detected. Lastly, the findings of our study are limited to study-specific geographical setting.

Conclusion

This national survey of HCPs trained in facilitating ACP conversations highlighted that about half of them had never facilitated an ACP conversation/documentation in the last year. HCP factors, namely lack of time for conducting ACP and ACP being a time-consuming process, were the most important barriers to facilitating ACP conversations. We suggest potential strategies to increase HCPs' engagement in ACP, which include simplifying the ACP conversation and documentation process, setting aside time in HCPs' schedules to have ACP conversations, and improving the ACP training framework. Future interventions should also address patient- and caregiver-related barriers to ACP conversations by

increasing their awareness and readiness in having ACP conversations and making ACP widely and easily accessible to all.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523000214>.

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Conflicts of interest. The authors declare that there is no conflict of interest.

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