



Challenges in providing end-of-life care consistent with documented patient preferences

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Background: Providing end-of-life care consistent with patient preferences is a major goal for advance care planning (ACP) programs. Despite the promise, many trials have failed to show that ACP improves patients' likelihood of receiving end-of-life care consistent with preferences. The reasons and challenges to facilitating end-of-life (EOL) care consistent with patients' documented ACP preferences remain unclear. Using data from Singapore's national ACP program evaluation, we aimed to understand health care professionals' (HCPs) perceived challenges in facilitating end-of-life care consistent with patients' documented ACP preferences.

Methods: We conducted 21 focus group discussions and 1 in-depth interview with HCPs trained in ACP facilitation and advocacy and involved in national ACP program implementation within public hospitals, public primary care clinics and nursing homes in Singapore. Data collection was stratified based on HCPs' role within the ACP program (ACP leads/champions, ACP facilitators, nursing home heads/ACP administrative staff) and type of institution (hospital, primary care clinic and nursing home). Each discussion included 1 to 8 participants. Discussions were audio recorded, transcribed verbatim and checked for accuracy. We analysed the data using thematic analysis framework in Nvivo 11.

Results: A total of 107 participants attended one of the discussions of which more than a third (35%) were physicians. We conceptualized five themes describing the challenges in implementing end-of-life care consistent with patients' documented ACP preferences: (I) conflict between honouring preference for comfort care and extending life; (II) ACP not reflecting patients' changing preferences or medical condition; (III) lack of health system resources to support and honour patient preferences; (IV) barriers to retrieval of ACP documents; and (V) rigidity of ACP documentation.

Conclusions: Although providing end-of-life care consistent with preferences may not always be feasible, future ACP programs should involve physicians and families for ongoing conversations, frequently update patients' ACP documents, involve clear and well-resourced plans for implementing patients' preferences, and incorporate flexible electronic systems to capture ongoing ACP conversations.

Keywords: Advance care planning (ACP); end-of-life; care preferences; qualitative; goal concordance

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Introduction

Over the past three decades, a tremendous amount of research has been conducted on advance care planning (ACP). The routine implementation of ACP is now a feature of many healthcare systems in developed countries. ACP is grounded on the principles of extending patient autonomy into future states of cognitive incapacity with the goal of facilitating end-of-life (EOL) care consistent with patients' preference (1). Several trials internationally have assessed the efficacy of ACP in facilitating EOL care consistent with preferences/goals, however, only a few trials conducted with elderly inpatients (2) and nursing home residents (3,4) have shown that ACP positively impacts EOL care consistent with preferences, with many randomized controlled trial (RCT) findings inconclusive or non-significant results (5-10). As a result, some have questioned the value of ACP or have called for rethinking the goals of ACP (11-14). As we rethink ACP, it is also important to understand the reasons why ACP programs, in many settings, did not facilitate EOL care consistent with documented patient preferences, and undertake efforts to address these implementation challenges.

Prior studies have highlighted several challenges to achieving EOL care consistent with documented patient preferences. First, a previous study has shown that physicians tend to be more supportive of preferences recorded in the ACP documents when it conformed to their clinical judgement and less supportive when it conflicted with their treatment plan (15). Second, our previous work with patients with advanced heart failure and advanced cancer patients has shown that patients' preferences change over time (16-18). If patient preferences change over time and ACP conversations are not regularly repeated, then it may not be possible for the treating physician to say with certainty that the preference recorded in the ACP document is what the patient may have wanted at that point in time. Third, provision of EOL care consistent with preferences can be hindered due to resource constraints (19). Fourth, studies show that physicians encounter difficulties in retrieving patient preferences from their medical records when making EOL decisions (20,21). Further, structured ACP programs incorporating rigorous training and engagement of all health care professionals (HCPs) as well as the general public can influence the culture of health care organizations to support patient preferences (22).

To better understand the real-world challenges confronting ACP programs in facilitating EOL care consistent with documented patient preferences, we used

data from a qualitative evaluation of Singapore's national ACP program. Modelled after the Respecting Choices Program (23), the first phase of the national ACP program was launched in 2011. The program was offered within in-patient settings in public hospitals. The program was expanded during the second phase of its implementation in 2017, to include public hospital out-patient clinics, primary care clinics and nursing homes throughout the country, making ACP accessible to everyone regardless of age or health status. Under the national ACP framework, HCPs completed one-day training for ACP advocacy and/or facilitation. Trained and certified healthcare providers facilitated and documented ACP in the national electronic health records. This ACP document can then be retrieved by healthcare teams in any public healthcare institution across Singapore when making EOL treatment decisions for patients. Despite a robust national ACP program, the challenges to facilitating EOL care consistent with patients' documented ACP preferences remain unclear. Understanding these challenges can benefit other countries implementing their own ACP programs. The main research question for this evaluation was: from the perspective of HCPs, what are the perceived challenges to provision of EOL care consistent with documented preferences? We present the following article in accordance with the COREQ reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-790/rc>).

Methods

Study design

Between January and April 2021, focus group discussions or in-depth interviews were conducted with HCPs involved in the national ACP program implementation within public hospitals, public primary care clinics, and nursing homes. HCPs who completed the ACP training for facilitation or advocacy under the ACP implementation framework and were currently employed in one of the public health care institutions in Singapore were eligible to participate. In addition, heads of nursing homes and ACP administrative staff implementing the ACP program from the nursing homes were included. HCPs not trained in ACP advocacy or facilitation were excluded.

Sampling

From an existing database of ACP trained HCPs within

public hospitals and primary care clinics in Singapore, we sampled participants based on their role within the ACP framework (clinical lead, clinical champion, ACP facilitator and ACP advocate), and department to ensure representation of all specialties implementing the national ACP program. Clinical leads oversee ACP implementation within each institution, clinical champions oversee ACP implementation within each specialty/department, ACP facilitators are trained HCPs (physicians, nurses or allied health professionals) who engage in ACP conversations, and ACP advocates are physicians trained to advocate for ACP. All clinical leads were invited, and we purposively sampled clinical champions to ensure representation of all departments/specialties under the ACP framework. Within each organization we included ACP facilitators with both highest and lowest number of ACP conversations facilitated. We invited heads, ACP facilitators and ACP administrative staff from each participating nursing home. All eligible participants were approached via email. A total of 45 participants declined as they were not interested or had time limitations due to manpower shortage. Among the others who agreed, 6 participants did not show up due to work commitments. Prior to the discussions, all participants signed a written informed consent for voluntary participation.

Data collection

A semi-structured interview guide was developed by the authors to broadly understand HCPs' perspectives on (I) awareness regarding ACP, (II) effectiveness of interventions to embed ACP into their organization's workflows, and (III) perspectives regarding effectiveness of ACP interventions to provide care consistent with preferences. The interview guide consisted of pre-determined questions on the above three topics; specific questions were however tailored for each category of HCP (ACP facilitators, ACP leads/champions, and ACP administrators and heads of nursing homes) (see [Appendix 1](#)). Probing questions were asked when required. Specifically, participants were asked about the current processes and systems in their respective organization to ensure patient preferences are honoured. Participants were also prompted to share their perception of a successful ACP program and factors that act as barriers and facilitators to successful ACP implementation. The guide was not pre-tested, but the content validity of the interview guide was assessed by experts overseeing ACP program implementation in Singapore. Each discussion included 1 to 8 participants and stratified based on

HCP category (ACP leads/champions, ACP facilitators, nursing home heads/ACP administrative staff) and type of institution (hospital, primary care clinic and nursing home), and described in *Table 1*.

A trained qualitative researcher experienced in moderating group discussions and in-depth interviews performed data collection. The interviewer had no direct relationship with the participants. Participants were aware of the purpose of the research, and this allowed for unbiased responses to be elicited. The discussions took place either in-person in a private room at the healthcare facility (hospital, clinic, or nursing home) or over a video conferencing platform (due to restrictions imposed by the COVID-19 pandemic). Field notes were recorded by a second team member present during data collection. Discussions lasted about 60–90 minutes, and were audio recorded, transcribed verbatim and checked for accuracy. Transcripts were not shared with participants due to their busy schedules.

Data analysis

We analysed the data using the six-phase guide in reflexive thematic analysis, a framework proposed by Braun and Clarke (24-26). Two team members independently read the transcripts to familiarize themselves with the data and conducted line-by-line open coding. Consensus meetings were held to discuss discrepancies between coders, and they were reconciled by repeated discussions, and verified by another study team member. Codes were grouped together to develop sub-themes, and the related sub-themes were organized under unifying broader themes. Analysis continued until code and theme saturation was reached. Themes were refined based on iterative discussions between all team members. We extracted relevant quotes to illustrate the main points within each theme. The qualitative analysis method followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (27). Nvivo 11 was used for data management.

Ethical approval

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013), and approved by the Institutional Review Board of National University of Singapore (No. NUS-IRB-2020-279). All participants provided written informed consent for participation and audio recording of the discussions.

Table 1 Participants by stakeholder group

| Discussion No. | Stakeholder group | Type of institution | Number of participants |
|----------------|--|---------------------|------------------------|
| 1 | Clinical lead & champions | Hospital | 5 |
| 2 | Clinical lead & champions | Hospital | 2 |
| 3 | Clinical leads | Primary care clinic | 2 |
| 4 | Clinical lead & champions | Hospital | 6 |
| 5 | Clinical lead | Primary care clinic | 1* |
| 6 | Clinical leads & champions | Hospital | 8 |
| 7 | Clinical lead & champions | Primary care clinic | 3 |
| 8 | Clinical leads & champions | Hospital | 3 |
| 9 | Clinical leads & champions | Hospital | 6 |
| 10 | Advance care planning (ACP) facilitators | Primary care clinic | 8 |
| 11 | ACP facilitators | Hospital | 6 |
| 12 | ACP facilitators | Hospital | 5 |
| 13 | ACP facilitators | Primary care clinic | 4 |
| 14 | ACP facilitators | Hospital | 4 |
| 15 | ACP facilitators | Hospital | 4 |
| 16 | ACP facilitators | Hospital | 5 |
| 17 | ACP facilitators | Hospital | 5 |
| 18 | ACP facilitators | Hospital | 6 |
| 19 | ACP facilitators | Primary care clinic | 4 |
| 20 | ACP facilitators | Nursing home | 7 |
| 21 | ACP administrative staff | Nursing home | 6 |
| 22 | Heads & ACP administrative staff | Nursing home | 7 |
| | | | Total: 107 |

*, there was only one clinical lead in this clinic cluster.

Results

Participant characteristics

Among 158 eligible participants invited, 107 provided informed consent and attended one of 21 discussions or in-depth interview (recruitment rate 68%). No participant attended more than one discussion. Mean age of participants was 43.3 years (SD 9.9) with 77 (72%) being females. Participants included physicians (35%), medical social workers (27%), nurses (17%), administrative staff (11%) and allied health professionals (10%). Their characteristics are summarized in *Table 2*.

Themes

We identified five themes (*Table 3*) reflecting HCP's perceived challenges in providing EOL care consistent with documented ACP preferences.

Conflict between honouring preference for comfort care and extending life

In Singapore, ACP is not legally binding, and physicians make decisions in patients' best interests in consultation with family members. Many physicians valued respecting patient preferences, and thus used the ACP document to guide their treatment decisions. On the other hand, some

Table 2 Participant characteristics (n=107)

| Characteristics | Value, n (%) |
|--|--------------|
| Age | |
| Years, mean (SD) | 43.3 (9.9) |
| Gender | |
| Male | 30 (28.0) |
| Female | 77 (72.0) |
| Professional role | |
| Physician | 37 (34.6) |
| Nurse | 18 (16.8) |
| Medical social worker | 29 (27.1) |
| Administrative staff | 12 (11.2) |
| Allied health staff | 11 (10.3) |
| Organization | |
| Hospitals | 65 (60.7) |
| Primary care clinics | 22 (20.6) |
| Nursing homes | 20 (18.7) |
| Specialty/Department | |
| Family Medicine/General medicine | 22 (20.5) |
| Geriatrics/Palliative care | 21 (19.6) |
| Internal Medicine/Neurology/Gastroenterology/ Hepatology/Hematology/Endocrine | 11 (10.3) |
| Social Work | 10 (9.3) |
| Oncology/Pediatric Hematology/Oncology | 4 (3.8) |
| Cardiology | 5 (4.7) |
| Nephrology | 5 (4.7) |
| Emergency Medicine | 2 (1.9) |
| Administration/Operations | 9 (8.4) |
| Others | 10 (9.3) |
| Missing | 8 (7.5) |

physicians when confronted with an ACP documenting patient preference for comfort care, often superseded patient preferences by providing them life-extending treatment/s believing that these treatments were in the 'best interest' for the patient.

Physicians were also guided by family members in making EOL decisions. In circumstances when the family members opposed patients' wishes, many physicians gave

in to family members' wishes to avoid conflicts. Many times, families were unable to manage their own emotions and actions in the heat of the moment. For instance, even if a patient had indicated a preference not to be sent to the hospital, upon seeing the patient suffering, the family member would panic and call the ambulance for patient to be transferred to the hospital.

Majority of participants voiced that many patients with a documented ACP indicating a preference to die at home were unable to have their preference honoured as caring for patient at home was a huge responsibility for the families who were often unprepared and unsupported to do so in the EOL period.

"...patient was given tube feeding. Medical team knew that patient has ACP, knew that patient didn't want tube feeding and did it anyway because in their opinion it was best for patient." (Participant code 10-6_ACP Facilitator, Physician, Hospital)

"...The children came and were not happy why this ACP was done without them. But the patient had very clearly said that he didn't want the children to be involved... So that was a conflict that we had and then the children said that 'no we want everything, all out'. So, despite knowing what was the discussion, the children refused to believe it and we had to scrap the whole ACP because we cannot fight, got no case to fight. The children is the main next of kin." (Participant code 7-3, ACP Facilitator, Nurse, Hospital)

"If I am breathless and I told in my ACP saying that please don't send me to clinic, the understanding is that my relatives will not send me and let me die at home. But when loved ones are seeing you breathless, and they cannot take it, they will call 995 and once the ambulance come so they send to hospital." (Participant code 12-1, ACP Facilitator, Allied Health Professional, Primary care clinic)

"Care logistics, for example maybe the preferences is to pass on at home, it is so complicated, and you need so much support at home and maybe the family is also not ready. Probably is more peaceful in nursing home or a hospital setting." (Participant code 13-1, Allied health professional, ACP facilitator, Hospital)

ACP not reflecting patients' changing preferences or medical condition

Patients' preferences changed over time with changes in their health status. This resulted in instances when care preferences recorded in the ACP document no longer reflected their current preferences. Patients' preferences also varied depending on the type of setting they were under. For those hospitalized, preferences were largely influenced by their current sickness, symptoms and

Table 3 Themes and subthemes reflecting challenges in providing end-of-life care consistent with documented preferences

| Themes | Subthemes |
|---|---|
| Theme 1: Conflict between honoring preference for comfort care and extending life | <ul style="list-style-type: none"> • Physician's clinical judgement superseding preferences • Absence of legally binding framework for advance care planning • Family overriding patient preferences & family conflicts • Inability of families to support end of life period at the home |
| Theme 2: Advance care planning (ACP) not reflecting patients' changing preferences or medical condition | <ul style="list-style-type: none"> • Patient's changing preferences over time influenced by medical condition and setting • Lack of periodic ACP review |
| Theme 3: Lack of health systems resources to support documented patient preferences | <ul style="list-style-type: none"> • Inadequate resources to support caregivers for home death • Lack of capacity in nursing home to support patient preferences |
| Theme 4: Barriers to retrieval of ACP documents | <ul style="list-style-type: none"> • Difficulties in accessing ACP by newly trained medical officers • Unavailability of full ACP discussion sheets • Ongoing conversations (incomplete or partial ACP) not available to medical team |
| Theme 5: Rigidity of ACP documentation | <ul style="list-style-type: none"> • Restrictive format of the published ACP document • Need to contextualize elicited preferences due to restrictive documentation |

experience with hospitalization.

Although the ACP workflows involved a yearly review of the patients' preferences to update their ACP documents, this was largely not done due to resource limitations including health care providers' time. Some organizations also did not prioritise continuing routine periodic review of ACP documents. Instead, patients were asked to contact their ACP provider whenever they wished to update their ACP documents. Most patients forgot to update their ACP document on a regular basis.

"To get someone in the acute setting (to do ACP) when they are very much in pain, I am not sure whether whatever decisions they make then will be the (same) one they (make) when they were not hurt. They (will) make different decisions then." (Participant code 12-1, ACP Facilitator, Allied Health Professional, Primary care clinic)

"So we do tell the patient that it is published and if they want to change they are free to come back any time to let us know. But my concern is that once they publish they forget about it." (Participant code 2-1, Clinical Lead, Physician, Primary Care Clinic)

Lack of health system resources to support and honour patient preferences

The lack of capacity with shortage of resources was observed in multiple settings. Many existing community care services also had limited resources and were often unable to support

caregivers in honouring patient preferences to die at home. Many participants perceived that nursing homes did not have the capacity and resources to support preferences. Even though some patients preferred to die in the nursing home, the COVID-19 pandemic posed difficulties in honouring patient preferences of place of death.

"I think there are certain nursing homes that you find that the management, I wouldn't say not supportive, but there is a lack of resources, probably resources are stretched and you find that these nursing homes will struggle to honor the ACP to a certain extent." (Participant code 5-9, Clinical Lead, Physician, Hospital)

"There are quite a few residents who prefer to pass away in the nursing home...But in circumstance that their condition deteriorates and let's say they have shortness of breath and they need to be transferred out and especially in this (COVID-19) pandemic ..., some of them unfortunately end up passing away in the hospital, and it conflicts with their preference in the PPC (preferred plan of care)." (Participant code 22-6, ACP Administrative Head, Allied Health Professional, Nursing Home)

Barriers to retrieval of ACP documents

Participants mentioned that it was not always easy to access and retrieve patients' ACP documents particularly for newly trained medical officers. Physicians were not able to access detailed ACP discussion worksheets from the National Electronic Health Records. They opined that if details were

overlooked, misconceptions could arise regarding patients' preferences. Electronic medical records systems also varied across hospitals, making it difficult for training doctors on short clinical rotations to understand how to retrieve ACP documents.

Additionally, the current national electronic system for ACP documentation only allowed completed ACPs to be documented and uploaded, while incomplete or partial ACPs could only be recorded in hospital case notes. Thus, many times, physicians making EOL decisions were unable to know if any prior ACP discussions have occurred and the details of those discussions. This was considered especially important when multiple healthcare providers were involved in patients' care or the patient was transferred from another facility.

"And the discussion worksheets, sometimes actually have lot of nuances and details but is not available to us...let's say if the patient's ACP was done in a nursing home or done at xxx polyclinic or in a hospital all we see is just that form with a tick box. We couldn't see the discussion work sheet." (Participant code 1A-3, Clinical Lead, Hospital)

When emergency team comes, definitely they want to send their loved one to hospital and they say how come they never check. So it is not possible for emergency team to check whether this patient has ACP done or AMD done, it's not possible." (Participant code 12-4, ACP Facilitator, Allied Health Professional, Primary Care Clinic)

"I think we should have a way to capture partial or ongoing conversations. Currently the uploaded forms are just the final forms so we cannot capture any partial conversations." (Participant code 5-2, Clinical Champion, Physician, Hospital)

Rigidity of ACP documentation

The rigidity of ACP form or final document limited a comprehensive documentation of patient preferences and the inability to record incomplete or partial ACPs. For instance, the ACP document has a restricting format consisting of tick boxes and a page limit, thus leaving little room to include details which help to contextualise elicited preferences or the varying viewpoints from family members that highlight family dynamics and conflicts. Hence, the ACP document did not always completely capture the essence of the ACP conversation, the conflicts in their goals and values, and documented preferences did not always reflect what patient had really expressed during the discussion.

"I think there is still room in the documentation for us to just capture the viewpoints of the various family members. Because I

think this may be useful for the future health care teams dealing with this patient towards the end of life, because they need to be aware of the family dynamics...and also just document the dynamics so that the future care teams can also take that into consideration." (Participant code 6-2, Clinical Champion, Physician, Primary Care Clinic)

"The form has to be contextualized because, as you know, the ACP form is very skimpy. You have to choose the boxes- comfort care, limited, full treatment. But it just says that if the heart stops, nothing about context you know." (Participant code 1B-1, Clinical Lead, Physician, Hospital)

Discussion

In this qualitative study evaluating the implementation of a national ACP program, we highlighted the challenges in facilitating EOL care consistent with patients' documented ACP preferences. Our results have implications regarding improvement of future implementation of ACP programs.

Results highlight that respecting patient autonomy requires significant buy-in from physicians and families, who have the power to override patients' documented preferences. Physicians and/or families may believe that certain treatments are 'standard of care' and in patients' 'best interests' or they may find it hard to 'let go' of the patient. A previous study has shown that treating physicians tend to be more supportive of preferences recorded in the ACP documents when it conformed to their clinical judgement and less supportive when it conflicted with their treatment plan (15). At the same time, a study has also reported that this limitation does not necessarily lower the appeal of ACP among many health care professionals (28), and that there is a recognition that patients' documented ACP is just one among many factors influencing EOL treatment decision making process. Physicians and families may also encounter difficulties interpreting patients' values, goals and preferences in relation to their actual EOL situation, especially if the clinical situation is vastly different from what was imagined at the time of ACP documentation.

Although EOL care consistent with documented preferences may not always be possible, to reduce potential for such conflicts during EOL treatment decision-making, firstly, it is imperative that treating physician/s and family members are involved during the ACP conversations. Especially for seriously ill patients, regular and ongoing ACP conversations between patients, physicians and family members, as patients' medical condition evolves, can help resolve conflicts in values and treatment preferences among

patients, families and physicians, and prepare patients and families for patients' EOL decisions. Patients may require substantial support and coaching in order to think about their values and priorities and to communicate them to their family members and physicians. Doing so, will ultimately make it more likely for patients to receive EOL care that are consistent with patients' ACP document. Secondly, a shift in the mindset of physicians is required to allow them to view their role from primarily curing illness and prolonging life towards providing patient-centred care. This is especially relevant in complex acute care settings where multiple medical teams are involved in patients' care and decisions. Thirdly, greater efforts need to be made to educate the public about the benefits of ACP and to normalize ACP conversations.

Our previous work both with patients with advanced heart failure and advanced cancer patients has shown that patients' preferences change over time (16-18). Patients often make future ACP decisions based on their current experiences, rather than what they are likely to experience in future. This is known as the 'projection bias' (29). Our current results further show that ACP documents are rarely revisited and updated to reflect patients' changing preferences. Future ACP implementations should thus incorporate systematic processes to make ACP a dynamic rather than a one-time intervention.

Our results further highlight that provision of EOL care consistent with preferences can be hindered due to resource constraints. The same has been highlighted by others (19). This is most likely to happen in the absence of a clear implementation plan for documented ACPs. Future ACP implementations should thus focus not just on conversations and documentations, but also incorporate a clear plan for meeting patients' preferences. For instance, for patients with a serious illness wanting comfort care and home death, a referral to palliative or hospice care should be made at an appropriate time, so that the family caregivers feel better supported to make decisions consistent with patient's care preferences. Future ACP programs should thus incorporate discussions on how documented preferences can be implemented for each patient with a serious illness including timely referral to an appropriate care pathway.

A well-designed electronic system exists in our setting to capture the essential details of the ACP conversations, make these details readily available when needed. This ensures coordination of care across the various health care organizations. However, the system could be further enhanced to also capture ongoing or incomplete

conversations, so that these conversations can be continued later or be used to inform EOL care decisions. The ACP document should be made more flexible to include information about patients' values regarding their care, rather than just focusing on treatment preferences. Doing so may make the document less rigid and easier to apply in actual clinical situations (30).

Strengths and limitations

This study has several strengths. We purposively recruited HCPs at all levels of seniority and role in ACP implementation, and from all public hospitals, primary care clinics and nursing homes across the country. This allowed us to assess a wide range of perspectives and increases the external validity of our results. Our qualitative methodology further allowed an in-depth exploration of HCPs' perspectives regarding ACP implementation. The study also has limitations. We did not include the perspectives of bereaved family members. Their views could have lent further insights regarding challenges in providing EOL care consistent with documented preferences. We acknowledge that not all departments were represented equally in the discussions and this may have influenced the responses. Further, our analysis did not include non-medical aspects of ACP (financial, funeral, etc.) that may influence end-of-life care. Since the project aims was to understand gaps in implementation of the national ACP program, we interviewed ACP-trained HCPs officially involved in the national ACP program. We acknowledge that the responses from HCPs not trained in ACP could have been different. Lastly, our findings may not generalize to other settings.

Conclusions

This study highlights the challenges in implementing EOL care consistent with patients' documented preferences. These include conflicts between honouring preference for comfort care and extending life, ACP not reflecting patients' changing preferences or medical condition, lack of health systems resources to support patient preferences, barriers to retrieval of ACP documents, and rigidity of ACP documentation. Although provision of EOL care consistent with preferences may not be feasible or advisable in many EOL situations, future ACP programs should involve physicians and families for ongoing conversations, frequently update patients' ACP documents, involve clear and well-resourced plans for implementing patients'

preferences, and incorporate a well-designed and flexible electronic system to capture ongoing or incomplete conversations.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013), and approved by the Institutional Review Board of National University of Singapore (Ref No. NUS-IRB-2020-279). All participants provided written informed consent for participation and audio recording of the discussions.

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