

## Breaking Barriers: Tackling Challenges in Achieving Patient-Centered End-of-Life Care

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### Abstract

**Background:** One of the main objectives of advance care planning (ACP) programmes is to provide end-of-life care in accordance with patient choices. Despite the hope, several studies have failed to demonstrate how ACP increases patients' chances of obtaining end-of-life care that is in line with their wishes. Uncertainty persists on the causes of and obstacles to providing end-of-life (EOL) care in accordance with individuals' recorded ACP wishes. We sought to comprehend health care professionals' (HCPs) perceived difficulties in providing end-of-life care in accordance with patients' documented ACP wishes using data from Singapore's national ACP programme assessment.

**Methods:** We held 21 focus group talks and 1 in-depth interview with HCPs participating in Singapore's national ACP programme implementation in public hospitals, public primary care clinics, and nursing homes. These HCPs had received training in ACP facilitation and advocacy. ACP leaders/champions, ACP facilitators, nursing home administrators/administrative staff, and type of institution (hospital, primary care clinic, and nursing home) were taken into account while stratifying the data collection. There were 1 to 8 people in each topic. Discussions were audio recorded, verbatim transcribing, and accuracy confirmed. Using the Nvivo 11 thematic analysis framework, we examined the data.

**Results:** A total of 107 people took part in one of the conversations, and 35% of them were doctors. In order to deliver end-of-life care in accordance with patients' recorded ACP choices, we conceptualised five themes: The ACP does not take into account patients' changing preferences or medical conditions. There are also resources lacking in the health system to support and honour patient preferences, obstacles to retrieving ACP documents, and rigidity in ACP documentation.

**Conclusions:** Future ACP programmes 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 adaptable electronic systems to record ongoing ACP conversations. Conclusions: Providing end-of-life care consistent with preferences may not always be possible.

**Keywords:** End-of-life; Health care; Patients; Palliative care; Cancer; Advance care planning; Treatment; Pain

### Introduction

Advance care planning (ACP) has been the subject of a tonne of study over the last three decades. In many wealthy countries' healthcare systems today, ACP is routinely used. ACP was developed with the objective of enabling end-of-life (EOL) care in accordance with patients' preferences. It is based on the ideas of extending patient autonomy into future phases of cognitive incapacity [1]. Several studies conducted internationally have evaluated the effectiveness of ACP in facilitating EOL care consistent with preferences or goals; however, only a small number of studies involving elderly inpatients [2] and nursing home residents [3] and showing that ACP positively impacts EOL care consistent with preferences have been found [5-10].

As a result, some have questioned the effectiveness of ACP or asked for a revision of its objectives [11-14]. Understanding the reasons why ACP programmes, in many locations, did not promote EOL care consistent with recorded patient wishes is crucial as we reconsider ACP. We should then make steps to solve these implementation issues. First of all, a prior research [15] has demonstrated that doctors often accept preferences listed in the ACP papers more when they align with their clinical judgement and less when they contradict with their treatment plan. Second, our past research with advanced cancer patients and advanced heart failure patients has demonstrated that patients' preferences alter throughout time [16-18]. The treating physician may not be able to claim with certainty that the preference

documented in the ACP document is what the patient may have desired at that point. Third, lack of resources may make it difficult to provide EOL care that is in line with desires [19]. Fourth, research demonstrates that it might be challenging for doctors to locate patient preferences in their medical records when making EOL judgements [20,21]. The culture of healthcare organisations may be influenced to promote patient preferences through organised ACP programmes that incorporate thorough training and engage all health care professionals (HCPs) as well as the general public [22]. We utilised data from a qualitative review of Singapore's national ACP programme to better understand the practical difficulties faced by ACP programmes in facilitating EOL treatment compatible with recorded patient preferences. The national ACP programme, which was based on the Respecting Choices Programme [23], debuted its first phase in 2011. Public hospitals provided the programme in in-patient settings. ACP was made available to everyone, regardless of age or health condition,

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during the second phase of its implementation in 2017, when it was expanded to include public hospital out-patient clinics, primary care clinics, and nursing homes across the nation. HCPs attended a one-day training course for ACP advocacy and/or facilitation as part of the national ACP framework. Healthcare professionals who had undergone training and certification supported ACP and recorded it in the country's electronic health records. When deciding on EOL therapy for patients, healthcare teams can consult this ACP paper at any public healthcare facility in Singapore. Despite a strong national ACP programme, it is still unclear what obstacles stand in the way of providing EOL treatment that is in line with patients' recorded ACP preferences. Other nations conducting their own ACP programmes can benefit from understanding these difficulties.

## Methods

### Study design

Focus group talks or in-depth interviews with HCPs participating in the national ACP programme implementation within public hospitals, public primary care clinics, and nursing homes were done between January and April 2021. Participants had to have completed the ACP training for facilitation or advocacy under the ACP implementation framework and be working for one of Singapore's public health care institutions at the time. The ACP program's administrative employees from the nursing homes and heads of nursing homes were also included. HCPs without facilitation or advocacy training for ACPs were not included.

### Sampling

In order to ensure representation of all specialties implementing the national ACP programme, we sampled participants based on their role within the ACP framework (clinical lead, clinical champion, ACP facilitator, and ACP advocate) and department from an existing database of ACP trained HCPs within public hospitals and primary care clinics in Singapore. Clinical leads oversee the implementation of ACP within each institution, clinical champions oversee the implementation of ACP within each specialty or department, ACP facilitators are trained HCPs (doctors, nurses, or other allied health professionals) who facilitate ACP conversations, and ACP advocates are doctors who have been trained to speak out in favour of ACP. To guarantee that all departments and specialties covered by the ACP framework were represented, we invited all clinical leaders and purposefully sampled clinical champions. We included ACP facilitators from both the greatest and lowest number of ACP talks mediated within each organisation. Each participating nursing home's administrator, ACP facilitator, and head were invited. Email invitations were sent to all individuals who qualified. A total of 45 people opted out because they had other commitments or were uninterested owing to a lack of staff.

Six of the others who agreed but were unable to go did so because of job obligations. Each participant provided a written informed permission for voluntary participation prior to the conversations.

### Data collection

To better understand HCPs' perspectives on (I) awareness of ACP, (II) effectiveness of interventions to integrate ACP into their organization's workflows, and (III) perspectives on effectiveness of ACP interventions to deliver care in accordance with preferences, the authors developed a semi-structured interview guide. ACP facilitators, ACP leads/champions, ACP administrators, and directors of nursing homes were the three categories of HCPs targeted by particular interview questions that were included in the interview guide. When necessary, probing inquiries were posed. Participants were specifically questioned about the procedures and mechanisms in place at their individual organisations to guarantee that patient choices are respected. In addition, participants were asked to describe what they thought made an ACP programme effective, as well as what they thought might help or hinder the implementation of an ACP programme. Although the interview guide was not pre-tested, professionals monitoring the ACP program's execution in Singapore evaluated its content validity. As shown in Table 1, each conversation included between 1 and 8 participants and was stratified by HCP category (hospital leads/champions, primary care clinic leads/ACP administrative staff, nursing home heads/ACP administrative staff, and ACP facilitators).

Data collection was carried out by a qualified qualitative researcher with expertise facilitating focus groups and in-depth interviews. There was no personal connection between the interviewer and the subjects. Because participants were aware of the study's goal, objective replies could be obtained. Due to limitations imposed by the COVID-19 pandemic, the conversations either took place in person in a private room at the healthcare facility (hospital, clinic, or nursing home) or over a video conferencing platform. A second team member who was present during data collection took field notes. The conversations were audio recorded, verbatim transcribed, and verified for correctness. They lasted between 60 and 90 minutes. Due to the participants' hectic schedules, transcripts were not distributed to them.

### Data analysis

Braun and Clarke's [24-26] six-phase framework for reflective thematic analysis to assess the data. To familiarise themselves with the data, two team members read the transcripts independently and carried out line-by-line open coding. Consensus meetings were organised to examine disagreements among the coders, and these disagreements were later resolved through further debate and verification by a different member of the study team. Sub-themes were created by combining codes, and the connected sub-themes were then

Table 1: Collection of data.

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

arranged under overarching, unifying themes. Up until code and theme saturation, analysis was conducted. Based on repeated talks among all team members, themes were improved. For the purpose of highlighting the key ideas within each subject, we selected pertinent quotes.

## Results

Out of the 158 eligible participants that were invited, 107 (or 68% of the total) gave informed consent and attended one of the 21 talks or in-depth interviews. No person took part in more than one conversation. Participants' average age was 43.3 years (SD 9.9), and 72% of them were female. Doctors (35%) medical social workers (27%) nurses (17%) office personnel (11%), and allied health professionals (10%) were among the participants, provides a summary of their traits. In Singapore, ACP is not legally enforceable, and doctors make decisions in accordance with patients' best interests after consulting with their families. The ACP paper served as a guide for many doctors when making treatment decisions because they emphasised honouring patient opinions. Family members also provided advice to doctors while deciding on EOL. Many doctors have acceded to family members' requests when they disagreed with those of their patients in order to prevent disputes. In the heat of the moment, families frequently struggled to control their own feelings and behaviours. For instance, even if a patient had stated that they preferred not to be brought to the hospital, the family member may panic when they saw the patient in pain and contact the ambulance to transport the patient to the hospital. Most participants agreed that many patients with ACPs stating a choice to die at home were unable to have their wishes followed since caring for patients at home was a major duty for the families, who were frequently unprepared and unsupported to do so throughout the EOL time. As patients' health conditions evolved over time, so did their choices. As a result, there were times when the care preferences listed in the ACP paper did not correspond to the patient's current preferences. The sort of setting that the patients were in also affected their choices. Hospitalised patients' choices were significantly impacted by their present illness, its symptoms, and previous hospitalisations.

Despite the fact that the ACP procedures called for an annual assessment of the patients' preferences to update their ACP documentation, this was usually not done owing to resource restrictions, particularly the time of the healthcare practitioners. Additionally, several organisations did not emphasise ongoing regular periodic evaluation of ACP documentation. Instead, individuals were instructed to get in touch with their ACP physician to update their ACP records. Most patients often neglected to update their ACP paperwork. Participants noted that it was often difficult for freshly trained medical officers to access and obtain patient ACP documents. The National Electronic Health Records' thorough ACP discussion worksheets were unavailable to doctors. They believed that if specifics were missed, misunderstandings about patients' preferences may result. Additionally, hospitals' electronic medical records systems differed, making it challenging for medical students and residents doing brief clinical rotations to comprehend how to acquire ACP documentation. Furthermore, the existing national electronic system for ACP documentation only permitted the documentation and upload of full ACPs; incomplete or partial ACPs could only be documented in hospital case notes. Because of this, it frequently happened that doctors making EOL judgements were unaware of whether or not they had previously had ACP talks or the specifics of those conversations. When several healthcare professionals were caring for patients or when a patient was being moved from another hospital, this was seen to be extremely crucial.

## Discussion

We emphasised the difficulties in facilitating EOL treatment in accordance with patients' stated ACP preferences in this qualitative research evaluating the execution of a nationwide ACP programme. Our findings have significance for bettering future ACP programme execution. The findings show that physicians and families, who have the authority to disregard patients' recorded wishes, must demonstrate a considerable level of buy-in if patient autonomy is to be respected. Families and/or doctors may find it difficult to "let go" of the patient or they may feel that a particular course of treatment is "standard of care" and in the patient's "best interests." According to a prior research [15], treating doctors often accept preferences listed in the ACP papers more when they line up with their clinical judgement and less when they clash with the course of therapy. However, a research has also shown that this restriction does not necessarily make ACP less appealing to many medical professionals [27,28], and that it is acknowledged that patients' recorded ACP is only one of several criteria determining the choice of EOL therapy. Patients' values, objectives, and preferences may be challenging for doctors and family to understand in light of their actual EOL position, particularly if the clinical situation differs significantly from the scenario that was anticipated at the time of ACP writing. Even though it might not always be able to provide EOL care in accordance with recorded preferences, it is crucial that treating physicians and family members participate in the ACP discussions to lessen the likelihood of such disputes throughout the decision-making process for EOL treatment. Regular and ongoing ACP discussions between patients, doctors, and families as a patient's medical condition changes can help resolve conflicts between patients' values and treatment preferences, as well as prepare patients and families for patients' EOL decisions. In order to consider their beliefs and objectives and express them to their family members and doctors, patients may need a lot of assistance and coaching. In the end, doing so will increase the likelihood that patients will receive EOL treatment that is compatible with their ACP agreement. In order for doctors to consider their mission as primarily delivering patient-centered care rather than primarily healing sickness and extending life, there must be a change in how they think. This is particularly important in complicated acute care settings when a number of medical teams collaborate on patient care and treatment choices. Thirdly, more has to be done to normalise ACP talks and educate the public about its advantages. Our prior research with advanced heart failure patients as well as advanced cancer patients has demonstrated that patients' preferences can shift over time [16-18]. Instead of considering what they are likely to encounter in the future, patients frequently base their future ACP decisions on their current experiences. The 'projection bias' is what is referred to as this [29]. Thus, systematic procedures should be incorporated into future ACP deployments to make it a dynamic programme rather than a one-time intervention.

Our findings underline the fact that lack of resources might make it difficult to provide EOL care that is in line with desires. Others have pointed out the same thing. This is most likely to occur if documented ACPs lack a clear implementation strategy. Therefore, future ACP implementations should include a clear strategy for accommodating patients' choices in addition to dialogues and documentation. For instance, a referral to palliative or hospice care should be made at the right time for patients with serious illnesses who desire comfort care and home dying. This will help the family carers feel more supported as they make decisions that are in line with the patient's preferences for care. The implementation of recorded preferences for every patient with a serious disease, including prompt referral to an appropriate

treatment route, should be discussed in future ACP programmes.

In our context, there is a well-designed computerised system that records the crucial information from the ACP talks and makes it easily accessible when required. This guarantees care coordination across diverse healthcare organisations. The technology might be improved still further to record continuing or cut off talks so that they can be resumed later or used to guide decisions about end-of-life care. Instead of only emphasising treatment choices, the ACP statement should be expanded to incorporate information about patients' values surrounding their care. By doing this, the document could become less rigid and simpler to use in real-world clinical scenarios [30].

## Limitations

This study has a number of advantages. We specifically sought for HCPs from all public hospitals, primary care practises, and nursing homes across the nation, representing all levels of seniority and roles in ACP implementation. This increased the external validity of our findings and allowed us to evaluate a wide spectrum of viewpoints. Additionally, our qualitative technique enabled a thorough investigation of HCPs' perceptions on ACP adoption. The study includes further restrictions. The viewpoints of grieving family members were not included. Their opinions could have added to our understanding of the difficulties in delivering end-of-life care in accordance with recorded choices.

## Conclusion

This study emphasises the difficulties in carrying out EOL treatment in accordance with patients' recorded preferences. ACP does not reflect patients changing preferences or medical conditions, a lack of resources in the health system to support patients preferences, obstacles to retrieving ACP documents, and rigidity of ACP documentation are a few of these. Future ACP programmes 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, even though it may not always be possible or wise to provide EOL care in accordance with preferences.

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## Conflict of Interest

Author declares no conflict of interest.

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