



**DukeNUS**  
Medical School

Lien Centre for  
Palliative Care

# Lien Centre for Palliative Care Policy Brief

## Rethinking Advance Care Planning

***Dr Chetna Malhotra***

Assistant Professor  
Lien Centre for Palliative Care  
Duke-NUS Medical School

**Editors:**

Prof Eric A. Finkelstein  
Dr Ada Portia M. Batcagan-Abueg

---

## Key Messages

1. Our studies provide evidence that patients' end of life care preferences change over time.
  2. This suggests that most patients do not hold strongly held preferences regarding what forms of end of life care they want.
  3. We discuss the implications of these findings and propose that it is time to rethink about how ACP can best be implemented to provide quality end of life care.
- 

## What is Advance care planning?

**Advance care planning (ACP)** is one of the most discussed interventions to promote end of life conversations. ACP is a process of planning for future health and personal care. It includes discussing one's personal beliefs and goals for care with their loved ones and healthcare providers. <sup>(1)</sup> It encourages individuals to document their preferences for treatment so that they can be taken into account when patients are no longer able to voice their opinions.

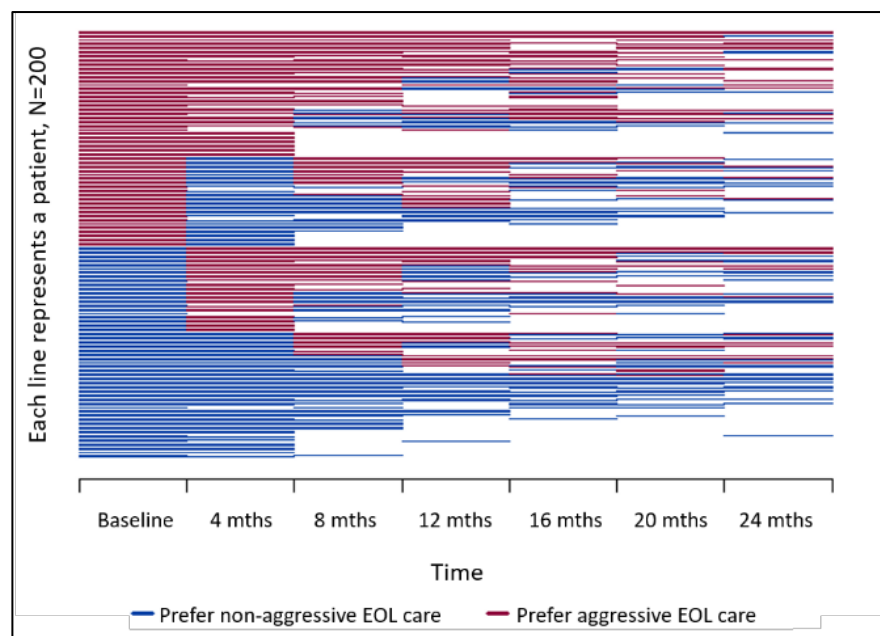
## What is the evidence regarding the Singapore model of ACP?

To evaluate whether the Singapore model of ACP, based on Respecting Choices Model, enables patients to receive end-of-life care consistent with their preferences, we conducted a randomized controlled trial among patients with advanced heart failure. We randomized 282 patients to receive ACP or usual care. We analyzed data of 89 deceased patients from the trial. We found that deceased patients in the ACP arm were not statistically more likely than those in control arm to have their preferences followed for end of life care (ACP: 35%, Control: 44%), or place of death (ACP: 52%, Control: 51%). A higher proportion in the ACP arm had wishes followed for cardiopulmonary resuscitation (CPR; ACP: 83%, Control: 62%) but again the difference was not statistically significant. <sup>(2)</sup>

While there can be several reasons why our trial did not find that the ACP program to be effective in facilitating end-of-life care consistent with patient preferences, one possible reason is that patients' preferences for end-of-life care change over time but ACP documentation is rarely updated over the course of patients' illness.

To understand why patients' preferences for end-of-life care change over time, think about the last time you have gone grocery shopping on an empty stomach and found yourself buying more food than what you will need for the coming week. In essence, our prediction for how much food we need for the coming week is being biased by our current state of hunger and we are making future decisions based on how we are feeling right now. This phenomenon is known as projection bias.

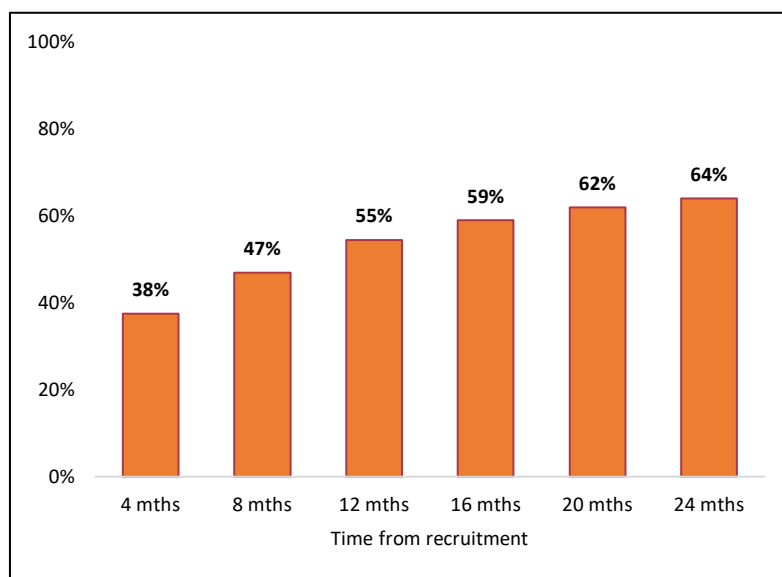
Projection bias is particularly problematic when there is a mismatch between what we are feeling at the moment and what we will feel in the future. It has important implications for ACP.



**Figure 1:** Preference for end-of-life care over time

If during ACP discussions, patients make decisions for future end-of-life care based on what they are experiencing or feeling in that moment rather than what they are very likely to experience at their end of life, then the preference they record in their ACP may not reflect what they may eventually want at their end of life. Given that patient's health status often fluctuates at the end of life, they are likely to change their preference for future end of life care frequently depending on what they are experiencing in the moment.

We used data from the above-mentioned randomized controlled trial to test the extent to which patients' preferences for end of life care change over time. We found that out of the 200 patients with advanced heart failure interviewed every 4 months over the course of 2 years, 64% changed their preferred type of end of life care (aggressive versus non-aggressive) at least once (**Figures 1, 2**) and 66% changed their preferred place of death at least once. Notably, change was not consistent in one direction and was influenced by patients' understanding of their prognosis (whether or not their illness can be cured) and their quality of life at the time of eliciting their preference. <sup>(3, 4)</sup>



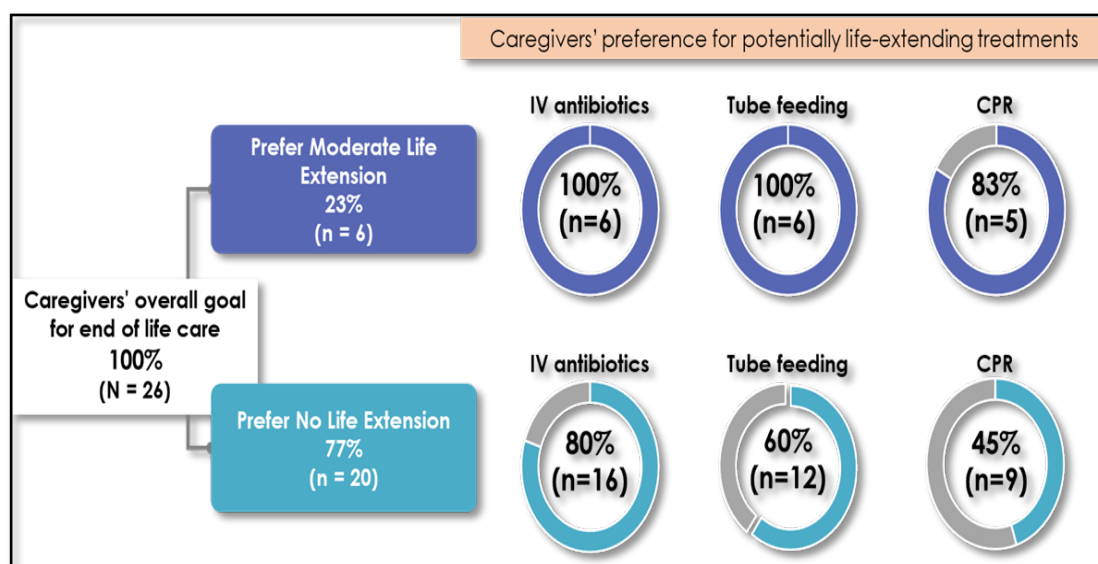
**Figure 2:** Proportion changing preference for end-of-life care at least once since recruitment

We also assessed this phenomenon using data from a prospective cohort study of patients with an advanced (Stage IV) solid cancer (COMPASS: Cost of Medical Care of Patients with Advanced Serious Illness in Singapore). Among 466 patients with an advanced cancer followed-up for a period of 2 years, more than a quarter changed their preferred place of death every 6 months. Again, change in preferred place of death was not consistent in one direction. Patients hospitalized in the last 6 months were more likely to change their preferred place of death to home. <sup>(5)</sup>

Lastly, we assessed whether preferences for life-extending treatments align with overall goals for care. We used data from a qualitative study with 26 caregivers of persons with severe dementia (part of the project PISCES: Prospective Longitudinal Study of Caregivers of Community Dwelling Persons with Severe Dementia). We asked caregivers about their overall goal of care for their care-recipient with severe dementia and their preference for intravenous (IV) antibiotics, tube feeding and CPR.

Most caregivers' (77%) overall end-of-life care goal was 'no life extension'. However, of these, 80% still preferred IV antibiotics for a life-threatening infection, 60% preferred tube feeding and 45% preferred CPR (**Figure 3**). <sup>(6)</sup>

Given preferences change over time and may not necessarily align with patients' values/goals, we argue that most patients/caregivers do not hold well-formulated and strongly held preferences regarding what forms of end of life care they want.



**Figure 3:** Overall goal and preferences for life-extending treatments among caregivers of people with severe dementia

## What are the implications of these findings?

Provision of end of life care consistent with patient preferences has long been considered as the hallmark of quality end of life care. But if patient preferences change over time, how then do clinicians best align end of life treatment decisions with patients' preferences? Can clinicians assume that what was recorded in a patient's ACP document was what that patient would have actually wanted at the time end of life decision is being made? How frequently should patients update their ACP documentation for the document to always reflect their current preference? Importantly, is it even possible to know with certainty what a patient would have wanted?

This is a huge dilemma for clinicians who are involved in making end of life decisions.

In a 2010 article, Sudore and Fried proposed that given all the complexities in pre-documenting patient preferences, instead of asking patients to make premature end of life care decisions, the main purpose of ACP should be to 'prepare' patients and

their surrogates to participate with clinicians in making the best possible in-the-moment end of life decisions. <sup>(7)</sup> End of life decision making is highly stressful for patients/and or surrogates. Studies report that patients and family members continue to remain unaware of patients' prognosis even in advanced stages of their illness. <sup>(8)</sup> End of life discussions between patients, family members and health care providers rarely happen. As a result, when it comes to making end of life decisions, family members report being unaware of what patient would have wanted and thus are often conflicted among themselves regarding the best course of action. <sup>(6)</sup>

Given all of this, we believe that it is important to prepare patients and their surrogates for end of life decision making. Therefore, ACP discussions should involve explicit discussions regarding patients' health status and prognosis. Health care providers can acknowledge patients' and surrogates' "hope" for the best possible outcomes, but at the same time encourage them to talk about what to do if things do not go according to what they hope for.

Patients' values, goals and preferences should be explored during ACP discussions to give both clinicians and surrogates a sense of what the patient values. But it should also be recognized that patients' preferences will likely change with time.

Importantly, ACP discussions should not be a one-time process. Patients' clinical condition is not static. Therefore, ACP discussions should happen frequently over the course of patients' illness, at least every time their clinical condition or treatment plan changes. It is only through ongoing ACP discussions can the patients and/or surrogates be more aware of their condition and be 'prepared' to make in-the-moment end of life care decisions alongside the treating clinician.

Documentation of preferences within medical records still holds merit for the sub-group of patients who express strongly held views and consistently express the same preference over a period of time despite change in their health condition and prognosis. But for most part, documentation of patient preferences should neither be considered as an end goal for an ACP discussion, nor should it be a key performance indicator for health care organizations and ACP practitioners.

Instead, research and policy efforts should be made to come up with alternate indicators to measure success of ACP implementation.


It is time that we rethink the purpose of ACP and how it can be best implemented to provide quality end of life care.

## References

1. Advance Care Planning. <https://www.aic.sg/care-services/advance-care-planning>
2. Malhotra C, Sim D, Jaufeerally FR, Meibo H, Nadkarni N, Hwa CN, Wong G, Cheng TB, Fen LJ, Ya-Ting CC, Finkelstein E. Impact of advance care planning on end-of-life care for patients with heart failure: Results from a randomized controlled trial. *Journal of Cardiac Failure* 2020 Jul;26(7):594-598
3. Malhotra, C., Hu, M., Malhotra, R. et al. Instability in End-of-Life Care Preference among heart failure patients: Secondary Analysis of a Randomized Controlled Trial in Singapore. *Journal of General Internal Medicine* 2020; 35, 2010–2016.
4. Malhotra C, Bundoc FG, Sim D, Jaufeerally FR, Finkelstein EA. Instability in preference for place of death among patients with symptoms of advanced heart failure. *J Am Med Dir Assoc.* 2021; 22(2): 349.e29-349.e34
5. Malhotra C\*, Koh LE\* (\*co-first authors), Teo I, Ozdemir S, Chaudhry I, Finkelstein E, Compass study team. A prospective cohort study of stability in preferred place of death among patients with Stage IV cancer in Singapore. *Journal of the National Comprehensive Cancer Network.* 2020 (forthcoming)
6. Malhotra C, Hazirah M, Østbye T, Pollak KI, Balasundaram B, Malhotra R, Tong KM, Hum AYM, Allen JC, Seow D, Yong JR, Yoon S, PISCES study group. Discordance between dementia caregivers' goal of care and preference for life-extending treatments. *Age and Ageing.* 2021 Apr 22;afab049. doi: 10.1093/ageing/afab049.
7. Sudore, Rebecca L., and Terri R. Fried. "Redefining the "planning" in advance care planning: preparing for end-of-life decision making." *Annals of internal medicine* 153.4 (2010): 256-261.
8. Finkelstein EA, Baid D, Cheung YB, Schweitzer ME, Malhotra C, Volpp K, Kanavarar R, Lee LH, Dent RA, Ng Chau Hsien M, Bin Harunal Rashid MF. Hope, bias and survival expectations of advanced cancer patients: A cross-sectional study. *Psycho-Oncology.* 2021 Mar 19.

---

### Duke-NUS Medical School

 8 College Road  
Singapore 169857

 +65 6516 7666  
Monday - Friday, 9am - 5pm