

**ABSTRACT**

**Advance Care Planning (ACP) is integral to good end-of-life care and there is rising awareness and interest in ACP in Singapore. This narrative synthesis sets out to examine effects of ACP on end-of-life care, factors influencing people to engage in ACP, healthcare professionals' attitudes towards ACP discussions, and the feasibility of ACP in primary care.**

**Keywords:**

**Advance Care Planning; Effects on End-of-life Care; Primary Care**

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**INTRODUCTION**

Surrogate decision-making is traditionally relied upon when loved ones lose the capacity to make decisions in serious illness. However, up to a third of surrogates cannot reliably predict the wishes of patients<sup>1</sup> and have identified their own values and preferences as influencing decision-making.<sup>2</sup>

There has been increasing advocacy for advance directives and ACP over the past 20 to 30 years. Advance Care Planning as a movement began in Western societies. This followed advances in medical science which prolonged lives, with variable outcomes, as well as high-profile cases such as Terri Schiavo and Nancy Cruzan. With the increased percentage of aged in society, there are rising numbers of people with chronic progressive illnesses. The landmark SUPPORT study highlighted poor quality of care at the end of life and spurred additional research on decision-making at this stage of life.<sup>3</sup> Factors considered important in a "good" death for patients, family and healthcare providers include pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion.<sup>4</sup> ACP is integral to this ideal.

Although legislative and regulatory bodies continue to promote advance directives, the overall prevalence of completed advance directives in the United States remains low.

In Singapore, ACP is not widely practised in the healthcare continuum. The Advance Medical Directive (AMD) Act was enacted in 1996. However, awareness and use of the AMD remains low<sup>5</sup> and it has had limited impact on end-of-life decision-making.

The National Guidelines for Palliative Care released in 2014<sup>6</sup>

advocated for all patients at the end of life to have access to ACP. Clearly, there is a need for a shift of focus from completion of documents to ACP as a process; an iterative conversation with patients and their loved ones. A comprehensive, flexible and systematic approach is required.

In 2009, the National Healthcare Group end-of-life taskforce invited Respecting Choices, a renowned ACP faculty from Wisconsin, USA, to Singapore to help train a group of healthcare professionals in ACP. In 2012, funding was disbursed through the Agency for Integrated Care to various regional health systems to run pilot projects on ACP. Since then, the practice of ACP has spread to all restructured hospitals, as well as some nursing homes, community hospitals, home care services and social care centres. As of third quarter 2015, the total number of completed ACP documents nationally was up to 2747.<sup>7</sup> These were mostly ACP discussions with patients with advanced illness in restructured hospitals.

As awareness of and interest in ACP rises, this narrative synthesis sets out to examine the following questions of relevance:

1. What are the effects of ACP on end-of-life care?
2. What factors influence people to engage in ACP as well as their views towards ACP?
3. What are healthcare professionals' attitudes towards ACP discussions?
4. What is the feasibility of ACP in primary care?

**What Are the Effects of ACP on End-of-life Care?**

Advance Care Planning outcomes are multidimensional and highly variable depending on the studies and objectives of the investigators. Different types of ACP interventions have been studied in various settings and populations. Broadly, there is evidence that ACP influences end-of-life care in a positive way.

A systematic review of the effects of ACP on end-of-life care reviewed experimental and observational studies (with control group) published between 2000–2012.<sup>8</sup> The search yielded 113 papers relevant for the review. Ninety-five percent of the studies were observational, 81 percent originated from the United States, 49 percent were performed in hospitals whilst 32 percent in nursing homes, 8 percent in the community, 10 percent in mixed settings, and 1 percent in the outpatient clinic. ACP interventions in the form of do-not-resuscitate orders (39%) and written advance directives (34%) were most often studied. Do-not-resuscitate orders and do-not-hospitalise orders decrease the use of life-sustaining treatments, including cardiopulmonary resuscitation measures; reduce hospitalisation; and increase the use of hospice and palliative care. Effects of advance directives (living wills and lasting

RAYMOND NG HAN LIP  
Consultant  
Palliative Medicine,  
Tan Tock Seng Hospital

powers of attorney) are more diverse but tend towards increased frequency of out-of-hospital care aimed at increasing the patient's comfort instead of life prolongation. Complex ACP interventions such as the Respecting Choices programme may be more effective than written documents alone and have been found to be associated with increased compliance with patients' wishes and satisfaction with care.

Patients who underwent facilitated ACP were more likely to have health directives.<sup>9</sup>

Patients who had prepared advance directives received care that was strongly associated with their preferences.<sup>10</sup>

A key study carried out in Australia which was published in 2010 randomised elderly patients to receive a complex ACP intervention (Respecting Patient Choices) versus a control group without ACP.<sup>11</sup> Of 56 patients who passed away by six months, end-of-life wishes were more likely to be known and followed in the intervention group (86%) compared with the control group (30%). In the intervention group, family members of patients who died had significantly less stress, anxiety and depression than those of the control patients. Patient and family satisfaction was higher in the intervention group.

Advanced cancer patients who report end-of-life conversations with their physicians were less likely to undergo ventilation, resuscitation, be admitted to or die in an ICU in the final week of life as well as have significantly lower healthcare costs in their final week of life. There was also increased use of hospice and palliative care (outpatient and inpatient).<sup>12</sup> Higher medical costs in the final week of life were associated with more physical distress (in the last week of life) and worse quality of death as reported by the caregiver.<sup>12</sup>

What is the evidence of the net effects of ACP on costs of care? A recent systematic review found that facilitated ACP has the potential to reduce net costs of care although the impact depends on the details of the ACP programme.<sup>13</sup> The primary goal of ACP programmes is to promote patient centred care near the end-of-life and not to reduce costs of care. To protect ACP discussions from undue influence of cost considerations, ACP programmes should invest in adequate training of facilitators, clear standards and transparency of objectives.<sup>13</sup>

Overall, there is increasing evidence that ACP strengthens patient autonomy and improves quality of care near the end of life. Internationally, there is a need for studies with an experimental design, in different settings, including the community.

### **What are people's views towards ACP and what factors influence them to engage in ACP?**

Research has shown that patients desire autonomy over end-of-life decisions<sup>14</sup> and expect physicians to initiate ACP conversations.<sup>15</sup>

A qualitative study in Pennsylvania looked at the kinds of factors that influenced individuals to engage in ACP.<sup>16</sup> It employed focus groups conducted with 23 older individuals and grouped themes into the following categories:

#### *Concern for self*

- 1) Autonomy: valued being in control of major life decisions.
- 2) Meaningful existence: wanted to maintain sense of dignity and respect.
- 3) Quality of life: wanted to be able to enjoy everyday life.
- 4) Likely outcome of treatment: wanted to understand and hope for chance of recovery.
- 5) Burden to self and suffering: wanted to avoid suffering.

#### *Concern for others*

- 1) Burden to others: wanted to avoid emotional and financial burden to loved ones.
- 2) Input from others: views of loved ones were important influences on motivation to engage in ACP.
- 3) Pressure from family: conversely, ACP was viewed as way for participants to exert their independence and actively counter pressure they felt from others.

#### *Expectations about impact of ACP*

- 1) Trust in the medical system: varying degrees of trust or distrust of the medical system influenced participants' engagement in ACP.
- 2) Predicted effectiveness: having information on the efficacy of medical treatments affected perceptions of the value of ACP.

#### *Anecdotes, stories and experiences*

- 1) Current events: stories in the media prompted participants to consider ACP and its relevance to their own situations.
- 2) Emotional response to caregiving: stories from participants as well as what they heard from others about the difficulty of physically and emotionally supporting someone who was fragile and dying.
- 3) Past experiences making decisions for others: witnessing the suffering of others and helping make decisions for them left strong impressions on participants.

These findings suggest that to encourage people to engage in ACP, healthcare professionals can reinforce the benefits of ACP in promoting autonomy, dignity, respect as well as patient-centred care. One can also help people to reflect on how ACP can alleviate the burden of loved ones' decision-making. Healthcare providers can draw on individuals' own experiences and observations regarding end-of-life experiences while facilitating ACP. The study also suggests that the perceived benefit of ACP is related to views about its expected efficacy as well as the level of trust in the medical system.

In a qualitative study conducted locally amongst family caregivers of patients with advanced illness,<sup>17</sup> there were similar views that ACP strengthens autonomy, improves quality of care at the end of life and prevents unnecessary suffering. There

was also recognition that death is a reality of life and that ACP helps one to prepare for this eventuality. These views on perceived benefits were borne out in other studies too.<sup>18, 19, 20, 21</sup> However, there are emotional and cultural barriers to discussing ACP for oneself and with loved ones.<sup>17</sup> Family caregivers identified an uncertainty of when and how to broach the topic. Some family caregivers struggled with truth telling and fear that open discussion would take away hope. There also exists a perception that it is not necessary to broach the topic of ACP when one is healthy, but only at an advanced stage of illness. This reluctance to consider ACP and tendency to postpone making plans for oneself till one is older or in poorer health exists both in oriental and non-oriental cultures.<sup>18, 19, 22</sup>

Contrary to some of these perceptions, most elderly would like to discuss their future medical care with their healthcare providers and facilitated ACP can enhance rather than destroy hope.<sup>20</sup>

Cultural views influence views towards ACP too. For example, there exists in some people the traditional Chinese superstition that talking about death and dying is inauspicious and brings bad luck.<sup>17</sup> In the East Asian context, Confucianism and the relative importance placed on an individual's relations with family and society have a deep influence on decision-making, especially at the end of life.<sup>17, 23, 24</sup> This highlights the importance of closely involving family members and loved one in the process of ACP.

Besides deferring to family members, patients may defer to physicians believing that physicians will know best what to do for them.<sup>17</sup> Other patient-cited barriers to completion of ACP included inconsistency with religious beliefs, too distressing to think about, difficulty completing documents, and planning to do it later.<sup>25</sup>

From these multidimensional views, it can be seen that ACP is a complex iterative process. Successful ACP cannot be measured by the completion of advance directives alone<sup>26, 27, 28</sup> and one should employ a tailored approach, taking into account individual readiness and attitudes as well as familial factors.<sup>29</sup> People's preferences may also change and there should be an attitude of regular review of ACPs.

Some key shared constructs relevant to ACP include: perceived susceptibility, the belief that one is vulnerable to developing the condition the behaviour will protect against; self efficacy; and the barriers to and benefits of changing one's behaviour.<sup>30</sup>

The Transtheoretical Model represented by stages of change as well as strategies to increase readiness for participation may be a useful framework to engage people in ACP.<sup>31</sup>

### **What Are Healthcare Professionals' Attitudes toward ACP Discussions?**

In a survey of healthcare professionals in the United States,<sup>32</sup>

72.6 percent of participants rated advance directives as fairly useful to very useful, while 58 percent noted that advance directives were followed most or all of the time. Logistical challenges as to why advance directives were not followed included situations in which advance directives existed but were not available or not reviewed, or the relevance to the condition of the patient was unclear. Process issues included conflict in family regarding expressed wishes in advance directives and disagreement among physicians and within the care team regarding prognosis and course of care. These highlight the importance of a robust system on capture and transfer of ACP information as well as continual education of healthcare professionals on ethical and professional roles in applying advance directives to the clinical context of the patient.

In a local cross-sectional survey amongst physicians and nurses exploring the importance of factors influencing the end-of-life care decision-making of healthcare professionals (HCPs),<sup>33</sup> respondents rated patients' wishes (96.6%), their clinical symptoms (93.9%), and patients' beliefs (91.1%) as very high. In all, 94.6 percent of the HCPs would respect a competent patient's wishes over the family's wishes when goals conflict. However, 59.9 percent of HCPs would abide by the family's wishes when the patient loses capacity even if the patient's previously expressed wishes are known. This highlights that whilst end-of-life care decision-making by HCPs appears largely patient centred, familial determination still wields significant influence. There is a need to closely involve family members in the process of ACP.

Regarding timing of initiation of ACP, most HCPs believe that it should be upon admission to a healthcare facility, diagnosis of a serious or terminal illness, when the patient has a poor prognosis, and when the patient is undergoing a serious procedure.<sup>32</sup> In the same study, approximately 50 percent of participants indicated that the annual routine checkup is an opportune time for this conversation.

Most physicians are not talking with their patients about their end-of-life wishes<sup>34, 35</sup> and most report they would not discuss end-of-life options with terminally-ill patients who are feeling well, instead waiting for symptoms or until there are no more treatments to offer.<sup>36</sup> In the outpatient clinic, physicians often missed the opportunity to engage in ACP despite openers patients provided that could have prompted such discussions.<sup>37</sup> The propensity to have such discussions may relate more to the personal preferences and level of comfort of patients, physicians, and family members than on the health status of the older adult.<sup>34</sup> Amongst renal HCPs locally, the main barriers for physicians were lack of time, concerns regarding family backlash, and the perception that patients were not prepared to discuss ACP.<sup>38</sup> Other physician barriers included perceived low health literacy of patients, lack of necessary skills, lack of privacy for discussion, and patients not sick enough. The perceived lack of resources for ACP, lack of public awareness, and difficulties talking about death existed among nurses too.<sup>39</sup>

Whilst ACP would be most pertinent when a patient is diagnosed with serious illness or deemed to have poor prognosis, it is often not the most ideal to bring this up when the patient is stressed and also undercuts the principle of ACP as an iterative process of reflection. There need to be systematic changes and educational impetus to bring the conversation upstream into outpatient clinics and when the patient is more well.

### What is the Feasibility of ACP in Primary Care?

The primary care provider is well poised to hold ACP conversations with patients and families with whom he/she may have longstanding relationships. Advance Care Planning should be initiated early when patients are more well, making the general practice setting ideal.

The local prevalence of ACP discussions amongst primary care providers is not known but likely to be very low.

Internationally, there is variable practice of ACP by primary care providers. ACP does not seem to be practised systematically for all community-dwelling older people and is usually targeted at specific patient groups with cancer, terminal illness, and Alzheimer's dementia.<sup>40</sup> The topics discussed in ACP may vary from advance directives to psychosocial topics and to exchanging opinions about situations that provided insight into the patient's end-of-life preferences. In general, primary care professionals do not practice ACP in a systematic way, and find it difficult to judge the right moment to start an ACP conversation.<sup>41</sup>

Family practitioners (FPs) vary considerably in their conceptualisations of ACP in terms of the content of ACP discussions and tasks for the FP. This can lead to confusion as the role of FPs may vary according to how ACP is conceptualised. A shared conceptualisation is needed to ensure successful implementation of ACP.<sup>42</sup>

In a systematic review of barriers and facilitators for FPs to engage in ACP, the following were the key barriers: lack of skills to deal with patients' vague requests, difficulties with defining the right moment to initiate ACP, the attitude that it is the patient who should initiate ACP, and fear of depriving patients of hope.<sup>41</sup> Interestingly, studies have shown that patients believe it is the physician's responsibility to initiate ACP, suggesting a gap in expectation between patients and FPs.

Stronger evidence was found for the following facilitators: accumulated skills; the ability to foresee health problems in the future; skills to respond to a patient's initiation of ACP; personal convictions about who to involve in ACP; a longstanding patient-FP relationship; and the home setting. Initiation of ACP in general practice may be improved by targeting the FPs' skills, attitudes, and beliefs, but there should also be commensurate changes in healthcare organisation and financing.<sup>41</sup>

To facilitate ACP in the primary care setting, there are ACP tools like advance directives and comprehensive programmes geared at improving end-of-life care in the generalist setting, such as the Gold Standards Framework in the United Kingdom.<sup>43</sup>

In a systematic review of studies designed to increase advance directive completion in the primary care setting, the most successful interventions incorporated direct patient–healthcare professional interactions over multiple visits. Passive education of patients using written materials (without direct counselling) was a relatively ineffective method for increasing advance directive completion rates in the primary care setting.<sup>25</sup>

Some professionals have created innovative computer-based decision aids for helping individuals to reflect on their values, goals and healthcare wishes, and to outline a plan for how they wish to be treated.<sup>44</sup> Locally, patients may be directed to the Living Matters website for a conversation primer.<sup>45</sup>

For ACP implementation to be feasible in primary care, there needs to be a combination of several interventions to systematise the initiation of ACP with patients:<sup>46</sup>

- 1) education of physicians;
- 2) systems to identify and trigger early discussions for eligible patients;
- 3) patient and family education;
- 4) structured formats to guide the discussions;
- 5) dedicated sections in the electronic health record for recording information; and
- 6) continuous measurement.

### CONCLUSION

ACP strengthens patient autonomy, facilitates patient-centred care, and improves quality of care near the end of life. It helps to decrease the burden of decision-making of loved ones when patients are seriously ill. As an iterative process, it may also enhance mutual understanding and relationships between patients, their loved ones, and their healthcare providers. There are multiple facilitators and barriers for patients and HCPs alike towards ACP. It may be helpful to view ACP as a staged conversation requiring a tailored approach for each individual.

It has been shown that when an ACP system is designed and improved over time, it is possible to achieve a high prevalence of advance care plans, these plans can be available to any provider in any setting of care. When these factors are achieved, it is possible to achieve a high rate of consistency between advance care plans and the treatment decisions made for the patient.<sup>47</sup>

Singapore is at the cusp of increasing awareness and interest in ACP. The challenge remains of making ACP a standard of patient-centred care at all points in the healthcare continuum.



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#### LEARNING POINTS

- **ACP strengthens patient autonomy and improves quality of care near the end of life.**
  - **Complex ACP interventions are more effective than written documents alone in improving ACP implementation.**
  - **There are multidimensional views of people and healthcare professionals towards ACP and interventions can be targeted at reinforcing facilitators and reducing barriers.**
  - **Successful implementation of ACP entails systematic education of patients, engagement of stakeholders, training of healthcare professionals, an efficient system of capture of ACP information, and continuous quality improvement.**
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