

UNIT NO. 2

PRIMARY CARE PHYSICIAN AS ADVANCE CARE PLANNING ADVOCATE

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ABSTRACT

Advance Care Planning (ACP) was introduced as part of patient care in the acute hospitals in Singapore in 2010, and has been gaining traction among hospital providers and their patients. The Agency for Integrated Care (AIC) hopes to strengthen ACP training and awareness in the social and community care sectors. Primary care physicians play an important role to introduce ACP, provide relevant information based on patients' health status, and offer advice, encouragement and guidance to enhance understanding, reflection and discussion. They can help patients and their loved ones identify issues in coping with chronic diseases or possible life-threatening conditions. When done well, ACP can uphold the respect and dignity of patients and allow for patient-centric care continuation. ACP conversation often begins by listening and exploring the patient's story. Physicians should be attuned to their patients' fears, worries and concerns, and identify triggers for opportunistic discussions about ACP with them. With adequate ACP and communication training, primary care physicians are probably best placed for timely ACP initiation.

Keywords:

Advance Care Planning; Primary Care; Communication; Decision-making

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Case Scenario A

Mr Aru, a middle-aged Indian gentleman, has been a patient with your clinic for diabetes mellitus. He has been on haemodialysis for the past three years. He has had diabetes mellitus for the past 11 years and has not been compliant with his medication. Instead, he spends time making a living to sustain his family of four and to achieve a reasonable middle-class status. His kidneys had succumbed to diabetic nephropathy and he was subsequently put on haemodialysis.

One day, his wife, Mrs Aru, came into your clinic with tears in her eyes. She let out, sobbing, that Mr Aru had been admitted into an acute hospital five days earlier. He had suffered a massive stroke that left him likely to be in a comatose state and bedbound. The primary medical team has been asking her about stopping haemodialysis altogether.

How would you help?

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Case Scenario B

Miss Chan SK, is the sister of one of your old classmates. She is an active 41-year-old lady who participates in trekking, travelling and doing volunteer community work. She has a warm personality and is known to be generous with her time for people who need help. She has been in good health otherwise. Miss Chan's sister, your classmate, called you up one day with a request for advice on care.

Apparently, Ms Chan had collapsed while she was volunteering in a nursing home. In the hospital, she was diagnosed with intracranial bleeding. Despite the initial success in management of the bleed, the post-operative course was stormy, with recurrent bleeds and infections. After about two months, she slipped into a coma, with total dependence for her Activities of Daily Living. Her distraught sister needed an opinion from you about her care.

How would you help?

FOR FURTHER DISCUSSION

- What are the issues?
- Who are those facing problems?
- How are they coping?
- How may they be assisted in decisions?

Common Features between the Cases

The two cases have difficult and challenging clinical scenarios that may pose professional and ethical concerns to healthcare providers. For the loved ones, they may face psychological distress regarding care decisions to be made in these situations.

Some Considerations to Bear in Mind When Making Difficult Medical Decisions**1. Define the medical problem**

The main reasons for arriving at a working diagnosis are twofold. Firstly, it allows prognostication. Secondly, it assists in the planning of interventions and management.

For the treating healthcare provider, the extent of disease progression and impact of disease on the quality of life may sometimes not have been fully appreciated. These may lead to situations of over-evaluation and treatment or under-evaluation and treatment.

Prognostication of specific life-threatening medical conditions may be determined using specific disease tools or general markers of disease progression. Dementia-specific and cancer-specific tools are some of the many that are available.

The United Kingdom GOLD Standard framework is available for use to guide the healthcare provider in giving prognostic information for organ failure: for example, heart failure, lung failure, advanced stroke disease, and dementia. The identification of a group of patients in the “no surprise” population that is associated with a not-unexpected mortality in the near future of 12 months is also a useful prognostic tool.

Understanding illness trajectories assists in planning for the care of a patient. There are four types of illness trajectories identified by Lynn et al. Projecting where the patient may be on the graph may be helpful to draw a sharper focus about the type of care that is desired for the stage of health.

Medical technology has been progressing and this has shifted the boundaries of care and expectations. For instance, a patient at current time with stage-4 colon cancer, if managed with surgery, the latest modalities of chemotherapy, and targeted therapy, may still enjoy a prognosis of survival over years. Haemodialysis has been extended to the geriatric age group. Elderly patients who are on dialysis without significant co-morbidities such as ischaemic heart disease, may have the benefit of a longer lifespan compared with those who declined it.

2. Attempt to manage better

The goal of interventions is to bring about a resolution of the problem(s) with return of full physical functional state if possible. Unfortunately, for chronic progressive diseases, such as the example of chronic kidney diseases deteriorating to end stage, there are limits to what conservative treatment without renal replacement therapy may do to provide symptom control. Ultimately, the question of more aggressive intervention of dialysis will be raised with the patient.

The patient should consider the net benefit of interventions in the light of known and potential benefits versus possible harm and side effects of evaluations and treatment.

Many factors affect decisions regarding interventions such as dialysis. Medical factors such as the presence of other medical co-morbidities and reduced physical function need to be taken into consideration. The impact of psychosocial, cultural, religious and financial issues are other factors that need to be included in the decision-making process. There has been a shift from paternalistic to self-autonomy decision-making models even in the local setting as evidenced by the Singapore Medical Council's Ethical Code and Ethical Guidelines.

Under usual circumstances, patients with intact capacity can participate and communicate the care plan to the medical team. Situations of cognitive deficit, “best interest” decisions are to be made by the medical team, especially in life-threatening situations.

“Best interest” decisions may be guided or arrived at after taking into consideration previous known expressions of a

patient's wishes, loved one's viewpoints and endorsed legal tools that may impact decision-making. Examples include the Advanced Medical Directive (Advance Medical Directive Act 1996) and Lasting Power of Attorney (Mental Capacity Act 2008, revised 2010). An Advance Care Planning (ACP) discussion is another possible tool to guide “best interest” care.

ACP discussions^{14,15,16} have been shown to reduce uncertainties in the care goals of patients and reduced emotional burden to loved ones. It may lead to less use of life-sustaining interventions with poor efficacy, to improved quality of life. There may also be earlier utilisation of palliative services to improve symptom control.

ACP discussion is not for everyone^{17,18,19} and may be viewed negatively by some patients, loved ones and even the healthcare providers. Nevertheless, ACP discussions, if done well, can uphold the respect and dignity of a patient and allow for patient-centric care continuation.

Is There a Role for an ACP Advocate in Primary Care?

Primary care has always been about advocating for improved overall health status for patients and offers opportunities for patient-centric care.^{17,18} The primary care doctor is well placed as a confidante who can help the patient and his loved ones identify issues in coping with chronic diseases or possible life-threatening conditions. He may better understand the disposition of the patient and the deeper thoughts of fears and concerns faced by him or her.

As an ACP advocate, the principal task undertaken by the astute physician will be to raise awareness of his patient and loved ones on the need for sensitive and respectful planning of the extent of care in potentially deteriorating medical situations. This planning will also include conversations helpful in assisting the patient to reflect and identify values and beliefs, and address fears and concerns. These can guide decisions on care goals. This is especially pertinent when a patient loses his or her decision-making capacity and is unable to participate in decisions on healthcare issues.

Initial reactions of patients and family to ACP conversations can be negative due to issues of taboo,^{21,22} perceived distress about discussing the dying process, and incompatibility of ACP with religious beliefs. Nevertheless, responses usually improve as their fears and concerns are clarified and resolved by trusted care providers over time. ACP is not a one-off conversation but an on-going one between patients, their loved ones and their care providers, focusing on the patients' values, beliefs and goals.

Demystifying the ACP Conversation Conducted by a Trained ACP Facilitator

The ACP conversation with a patient and his or her loved ones is a dynamic and interactive process. There are three components to the ACP process — understanding, reflection,

and discussion. Though the ACP advocate is not expected to facilitate and be present during all the patients' ACP discussions, and documented their decisions, it is important for primary care providers assuming the role of advocate to be familiar with these components.

In order to initiate thoughtful ACP conversations, the trained facilitator helps patients understand why ACP is important for any adult, the components of the ACP discussion, the benefits of planning, and the potential consequences of not planning.²³ The facilitator assists patients to explore their fears, concerns and perceptions leading to a deeper level of understanding about their values and beliefs.

Patients will need to understand what kind of ACP decisions they are required to make. A healthy adult, for example, would not need to plan for the same decisions as a patient with end-stage renal or heart failure. Thus, patients should have a deeper understanding of their medical conditions, their severity, various types of treatment that are currently undertaken, and other potential interventions.

The next component of the ACP process is a values discussion aimed at exploring and identifying patients' values, goals, and care preferences in general. Hammes & Briggs²³ propose the following effective techniques to engage people in this reflection process. They include encouraging patients to (a) share their personal stories; (b) explore experiences with loved ones who have been seriously ill and what was learned through these experiences; and (c) describe what "living well" means to them. Engaging patients to reflect on these questions and helping them to express their personal beliefs, values and goals provides them with a framework to weigh the benefit and burden of future healthcare decisions.

The final component focuses on the on-going discussion between patients, their nominated healthcare spokespersons, their significant others and healthcare providers, among others. An effective ACP process identifies communication channels that need to be opened and offers suggestions for how to initiate discussion with others.²³

Locally, ACP discussions are held with trained facilitators which may take more than one session and decisions documented in locally standardised forms. These are not legal forms but nevertheless carry the same weight as other clinical notes for care provision and considered under the common law.

Primary Care Physician as ACP Advocate — Initiating an ACP Conversation

Primary care providers play an important role in introducing ACP, providing relevant information based on patients' health status, and offering advice, encouragement and guidance to enhance understanding, reflection and discussion. Contemplation of future treatment and care issues by patients

often starts with recent serious illness, hospitalisation, major surgery, worsening symptoms and functional decline, or the experience of ACP involving significant others. In the course of seeking treatment, patients often provide verbal cues that communicate their worries, fears and concerns, which are possibly reflections of their current state of life. Care providers should be attuned to these verbal cues and identify triggers for opportunistic discussions about ACP with their patients. **Table 1** depicts common verbal cues expressed by patients to communicate thoughts about their future healthcare concerns and worries.

"I don't want to be a burden to my family."
"I've had enough; I do not want to continue treatment."
"What happens if you stop dialysis?"
"I really cannot take anymore medications."
"What if my condition gets worse?"
"I was thinking of writing a will."
"Person B was a good friend; I don't want to die like that."
"I've lived a good life, I am satisfied and at peace."
"I don't want to be hooked up to a bunch of machines."
"Is stopping treatment as good as committing suicide?"

Table 1. Common verbal cues that reflect patients' fears and concerns

It is helpful for care providers to take a non-expert's stance when engaging patients to elaborate on their worries, fears and concerns. A simple way to elicit responses and encourage patients to talk about their concerns is to reply, "I hear what you are saying, can you tell me more?"

The Narrative Approach to ACP Conversation

The ACP conversation often begins by listening to and exploring the patient's story. The narrative approach is well documented in the literature as a valuable strategy to gain insight into one's own worldview.^{25,26} The use of narratives will enable care providers to understand the patient's goals, values, and beliefs. These insights can have a powerful, positive impact on the understanding needed to make future healthcare decisions and on the motivation to plan.²⁴

There are many ways to encourage conversations about one's stories. **Table 2** offers helpful question-statements that could be employed to initiate conversations with patients and their significant others to talk about ACP. These question-statements seek not only to elicit information from patients, but to communicate the care and concern of the inquirers towards the recipients. A noteworthy distinction between caring physicians and their lesser counterparts is how and when these statements are made. Statements made in an unhurried manner and appropriately encourage conversations.

Others made simply as passing comments or in an interrogative manner rarely produce any genuine interactions.

• How are you coping with your current medical condition?
• Who are aware of your medical condition?
• Do you have anyone whom you can talk to about your concerns and fears?
• I wonder if you have spoken about your (patient's) future treatment preferences and goal(s)?
• I am wondering if you ever thought about having a person to speak on your behalf if you suddenly became incapable of communicating your wishes to your doctor or nurses?
• As we are talking about this topic (a medical condition or treatment plan), how do you feel?
• I can see that you are doing your best to take care of your (loved one), however have you ever talked to him/her about his/her wishes and treatment preferences?
• Could you share with me about your experience of being seriously ill?

Table 2. Helpful statements to initiate ACP conversations

Resources to Facilitate Advance Care Planning Conversations

In Singapore, primary care providers can contact the Agency for Integrated Care (AIC)—the national coordinating body for Living Matters ACP programme—for online resources and referral support. Physicians may provide useful information such as printed ACP materials to guide patients and their families to reflect further about this topic.

For more challenging situations or discussions encountered, or as a continuation of the conversation, the physician can refer the patient and his/her loved ones to their specialists in hospitals with ACP facilitators to further explore issues. Locally, AIC has also engaged restructured hospitals to train healthcare providers to facilitate ACP conversations for patients with complex medical conditions, social and/or family relationship issues.

But, more can be done to educate healthcare professionals and patients, and promote a paradigm shift that ACP is not just about end-of-life care, but should be a norm for every healthy person. Therefore, AIC has also increased efforts to engage and equip community care providers with relevant knowledge and communication skill set to facilitate this meaningful conversation. Primary care physicians willing to be trained as ACP facilitators may also sign up for ACP facilitation workshops.

CONCLUSION

Primary care physicians have been advocating for the overall health and well-being of their patients and families through early diagnoses, timely interventions and assisting them in adoption of preventive strategies usually over a long period of time. They are in a position to raise awareness of the need for

planning of care for future medical crises among their patients and their loved ones. Advance care planning conversations may be that platform whereby patients allow their loved ones a deeper understanding of their care preferences before capacity is lost and they are faced with life-threatening situations.

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LEARNING POINTS

- **ACP conversations are guides to desired medical care.**
 - **ACP conversations seek to uphold the respect and autonomy of patients.**
 - **ACP awareness can be initiated in primary care.**
 - **Raising ACP awareness need not be difficult.**
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