

ADVANCE CARE PLANNING: LET'S TALK ABOUT YOUR PREFERENCES FOR CARE AT THE END OF LIFE

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ABSTRACT

Advance care planning is not widely practiced in the local context. When used appropriately, it is a tool that encourages deeper conversations about issues once deemed taboo to talk about and promotes patient centered care at the end of life. There are challenges that face the initiation of advance care planning discussions including physicians' apathy and inadequacy of training. Successful advance care planning will entail sensitive discussions of the patient's preferences and values that influence care at the end of life, clear documentation, regular review over time and application of the advance care plans to real situations. Primary care physicians can initiate advance care planning discussions with their patients who are usually in stable health.

Keywords: Advance Care Planning, Primary Care, Advance Medical Directives.

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INTRODUCTION

In this article, I explore the definition, benefits and types of advance care planning, how advance care planning is practiced locally, the challenges facing the movement and how one can successfully initiate and conduct advance care planning discussions. Where appropriate, case examples I encountered in my practice are described.

Case 1

Madam M was a 55-year-old Indian female who was diagnosed with locally advanced cholangiocarcinoma. She was deemed unsuitable for major surgery and underwent palliative stenting of her bile duct. Her son, Mr J, decided that she should not know her diagnosis of cancer as he felt it that she would become depressed as a result. She subsequently developed recurrent hepatobiliary sepsis necessitating bouts of systemic antibiotic treatment. Microbiology culture results from bile fluid grew multiresistant Klebsiella and Escherichia coli. During her hospital admissions, the medical team explained to Mr J that repeated and prolonged use of potent antibiotics would

have declining benefit over time. Mr J requested that everything possible be done to treat his mother and maintained that he does not wish his mother to be told of her primary diagnosis. In her last admission, Mdm M was deeply jaundiced and was drowsy from septic encephalopathy and hepatobiliary sepsis. She also developed acute renal failure. Blood culture grew multiresistant Escherichia coli. Mr J was keen on aggressive treatment and she was commenced on intravenous imipenem as well as intravenous fluids and dopamine to support her blood pressure. Her condition continued to deteriorate. After discussion with her family and communicating to them about the futility of treatment, Mdm M was terminally discharged and passed away shortly after at home.

Death is not a topic that everyone is comfortable talking about, much less one's own death. As illustrated by the case example above, one may be struck with a terminal illness and be rendered incapacitated to make decisions about care and preferred options. Many of us would trust our family to make such decisions in our best interests. However, that may not always hold true. In Madam M's case, the diagnosis of advanced cholangiocarcinoma was kept from her by her family and she did not have the opportunity to indicate her wishes with regards to end of life care including the extent of treatment. She may not also have made the emotional adjustment to the terminal nature of her illness, being told by her sons that she would be better with treatment.

WHAT IS ADVANCE CARE PLANNING?

Advance care planning (ACP) is a process whereby patients discuss, state and document their values and wishes regarding medical care with their caregivers, in the event that they are incapacitated from making decisions on their own¹.

Its foundation lies in the ethical principle of patient autonomy. It is not a single isolated event nor is it just the making and implementation of a document. Advance care planning is a continual process whereby a patient's preferences are discussed in advance with his/her family and physicians, recorded and honored. It is not just about resuscitation orders, the choice of setting of care, planning of funeral and memorial services and decision with regards to organ donation. On a deeper level, advance care planning is an exploration of what is important to a patient and endeavors to patient centered care in dying as in living. However, there are pitfalls in the process of advance care planning. Preferences and values can change over time and advance care plans may not always be implemented.

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WHAT ARE THE BENEFITS OF ADVANCE CARE PLANNING?

In the SUPPORT study which involved more than 9000 patients in 5 teaching hospitals in the United States of America during the 1990s, it was found that discussion of end-of-life decisions before death was rarely carried out. More than a third of patients who passed away spent at least 10 days in the intensive care unit and forty-six percent of patients were mechanically ventilated within 3 days of death. In this study, terminally ill patients had moderate to severe pain at least half the time². The use of inappropriately aggressive treatment in the terminally ill and late implementation of the palliative approach in many acute hospital settings is borne out in similar studies elsewhere³.

Advance care planning ensures that a one's wishes are honored in case one is unable to make independent decisions. The process allows the patient to prepare for the eventuality of debility and death and to some extent retain control over this part of his/her life. In exploring and discussing issues of dying and death with significant others, the patient can achieve some peace of mind and a sense of preparation for the inevitable. The patient is better able to make emotional calibrations to his/her declining health and ensure that practical matters such as settling bank mortgages are taken care of. In designating a health care proxy, one can be assured of a trusted loved one to make decisions on one's behalf. The patient can also be in a better position to "let go" and caregivers will have less distress in making decisions when they know the patient's wishes and preferences. Research shows that most elderly would like to discuss these issues with their healthcare providers⁴. Channels of communication are open between patients, their families and their healthcare providers, helping to maintain trust.

WHAT ARE THE TYPES OF ADVANCE CARE PLANNING ?

In advance care planning, there are broadly two result: an advance statement and an advance decision⁵.

- 1) An advance statement describes a patient's wishes, likely plans and preferences for what would happen to him/her in future care. It guides the physician in caring for the patient as an individual and is usually not legally binding.
- 2) An advance decision is a legally binding document that describes what a patient does not want to be done for example in an advance medical directive.

Advance care plans can be verbal or written, although written plans are preferred to avoid ambiguity. Besides using statutory documents, advance care plans can also be recorded in other forms, for example in a letter from a child to his parents and healthcare professionals.

HOW IS ADVANCE CARE PLANNING PRACTISED IN SINGAPORE?

The advance medical directive

In Singapore, advance care planning is not widely practiced. The current legal framework for advance care planning is represented by the Advance Medical Directive Act which was enacted in 1996⁶. The Advance Medical Directive (AMD) is a legal document signed by a person in advance to indicate that he does not wish to have any extraordinary life-sustaining treatment to prolong his life in the event that he becomes terminally ill and mentally incapacitated.

Case 2

Madam C was a 74-year-old Chinese lady with a known history of motor neurone disease. The disease affected her swallowing and she received nutrition through a percutaneous gastrostomy. She was largely chair bound and assisted in her activities of daily living. Through her neurologist, Madam C signed the advance medical directive. She was admitted to the observation room of the hospital emergency department for a blocked PEG tube. While awaiting the review from the gastroenterologist, she became apnoeic and pulseless. The emergency department staff resuscitated her with cardiopulmonary massage and intravenous adrenaline. Shortly after, her family expressed that Madam C has made an AMD and that they do not want her to be intubated. On transfer to the general ward, her Glasgow Coma Scale was 12 and the diagnosis was cardio respiratory arrest possibly from pulmonary embolism or acute coronary syndrome. She was referred to the palliative team and was commenced on morphine for shortness of breath. A few days later, she was transferred to an inpatient hospice.

An AMD can only be executed when a patient is certified with a terminal illness; needs extraordinary life-sustaining treatment; and is not capable of making rational judgment.

Anyone who is aged 21 years and above, and of a sound mind can make an AMD. Any person who wishes to make an AMD can do so by completing a prescribed AMD form, signed in the presence of two witnesses, and return it to the Registrar of AMD.

The AMD has many safeguards to protect against any potential misuse. To download the AMD form and related information on the AMD Act, one can visit the website <http://www.moh.gov.sg/mohcorp/forms.aspx?id=94>.

In Singapore, as of 2008, less than 10,000 have signed the advance medical directive since its inception in 1996⁷. In 2008, there was a lively debate and renewed public interest in the issue of palliative care and dying well. Members of the public wrote to the press to express their views with some supporting legally sanctioned euthanasia while others vehemently opposed euthanasia. Some people confused advance medical directives with euthanasia⁸. The health minister in Singapore, Mr Khaw Boon Wan, publicly acknowledged that "we have been too cautious and unduly squeamish" in promoting the concept of

advance care planning and that the number of people who have signed an advance medical directives is a "terrible" figure⁷. Calling for barriers to be removed, Minister Khaw suggested changes to the AMD act to foster more open discussion between doctors and patients⁹.

Changes have been made to simplify the process of signing an advance medical directive. When previously the forms are available in hospitals and clinics, members of the public can now download the form from the internet. There were also calls to simplify the process by doing away with the need for a doctor to witness the signing of an AMD.

A campaign named "Life Before Death" was launched since 2006 by the Lien Foundation in Singapore to raise the awareness of Singaporeans towards palliative and hospice care as well as end of life issues. The campaign in 2008 focused on starting "dialogues" on dying well through documentaries, radio shows, a website (www.lifebeforedeath.sg) and a street poll of the attitudes of Singaporeans towards death. Prominent figures stepped forward to lead the campaign to activate Singaporeans to reflect on and break the "conspiracy of silence surrounding death"¹⁰. At a press conference, Mr Gerard Ee, a name closely associated with charity in Singapore who won a battle against colorectal cancer himself said "We needn't be afraid to talk about death. On the contrary, it poses chances for reflection, reconciliation and regeneration".

What was heartening in the public discussion was that it was recognized that advance care planning is not a game of numbers in terms of advance medical directives. Minister Khaw said that "The key really is not so much about AMDs and how many people sign up, as (it is about) advanced planning, particularly among the terminally ill.....And the earlier it is discussed in an open manner, it should help the terminally-ill and their family members".

The Mental Capacity Act

In Singapore, the Mental Capacity Act was passed in Parliament in September 2008 to allow Singaporeans to appoint people as proxy decision makers in the event that they are mentally incapacitated. This will come into effect when the Office of Public Guardian and the Code of Practice is established some time this year. Through a statutory mechanism known as the Lasting Power of Attorney, an individual or "donor" can appoint a trusted person or "donee" to make decisions in matters related to his financial affairs, personal welfare and/or healthcare should he lose his mental capacity. The Act is important as the number of patients with dementia will rise with the aging of society. At the same time, the Act allows people to appoint proxy decision makers in advance care plans should they become mentally incapacitated from terminal illness.

Not just about advance medical directives

However, advance care planning is not just about advance medical directives or appointing surrogate decision makers

under the Mental Capacity Act. It is, in its broadest sense, an exploration of what is important to an individual nearing the end of one's life journey. It involves both informal communication and formal documentation on matters such as one's preferred place of dying and death, one's values and one's wishes with regards to end-of-life care. It is a dynamic process as a patient's preferences and values can change with time and circumstances. The thinking ahead template used under the Gold Standards Framework programme in the United Kingdom is an example of a feasible and practical document. It can be downloaded at: <http://www.goldstandardsframework.nhs.uk/images/cmsdocs/ACP%20Sept07%20v14.pdf>

In other countries

Advance care planning is a more mature process in countries such as the United States, the United Kingdom, Canada and in Australia. In the United States of America, the Patient Self-determination Act was passed in 1990 requiring patients to "be informed of their rights to accept or refuse medical treatment and to specify in advance the care they would like to receive should they become incapacitated"¹. In 1997, the American Medical Association's Council on Ethical and Judicial Affairs identified advance care planning as an important part of standard medical care¹. In the United Kingdom, advance care planning is identified as an essential element of the end-of-life care strategy of the National Health Service.

WHAT ARE THE CHALLENGES AHEAD?

Certainly, the first barrier to advance care planning will be a lack of awareness and knowledge of what it means, its benefits and how to go about doing it. In a systematic review by Ramsaroop et al on what one need for success of completion of an advance directive in the primary care setting, physician related barriers cited included perceived low health literacy of patients, inadequate skills, lack of privacy to discuss with the patient and patients who are not ill enough¹³. Patient related barriers cited included difficulty in filling the documents, procrastination of discussion, unwillingness to consider end-of-life issues due to perceived distress and incompatibility of advance care planning with religious beliefs.

Contributing greatly to the failure to plan is the issue of diagnosis disclosure or a lack of it. Locally, data from surveys done in the 1990s revealed that up to 40% of patients with terminal illness were not told of their diagnosis and up to 84% of healthcare professionals will collude with family members in not telling the patient¹⁴. Particularly in the case of cancer, family often cite a desire to protect their loved one from worry and depression in throwing a cloak of non-disclosure. In a paper by Lee et al, suggested steps of dealing with collusion include the recognition that it arises out of love and concern for the patient, acknowledging that the family knows the patient better, exploring deeper reasons for non-disclosure and discussing the harm of non disclosure and benefits of disclosure with the family¹⁴.

Other barriers to talking about death and dying are a perception that it is disrespectful and insensitive to talk about this with one's elderly loved one, particularly in the Asian culture¹¹. A caregiver explained: "People think that if you talk about negative things like death, such things could actually happen"¹¹.

Research has shown that prognosis disclosure and advance care planning conducted in a sensitive manner facilitated realistic hope and increased willingness to discuss end of life issues as well as helped patients to focus on future goals of care¹². Different people will have different attitudes towards advance care planning and people with higher educational levels were found to be more likely to prepare advance directives¹⁵.

Central to the sensitive process of advance care planning is good communication at every level between the healthcare professional and the patient and his/her family. It is an individualized process with an inherent recognition that cultural factors impact on the approach for each patient¹¹.

As mentioned, there are physician related barriers to advance care planning as well. Physicians may not recognize the benefits of advance care planning and find the process time consuming and troublesome. Papers have also cited an over reliance on the physician to initiate discussion on such issues on the part of the patient¹¹.

Adding to the debate is the confusion of advance care planning with euthanasia. A flurry of letters to the press last year revealed a misperception of advance medical directive as euthanasia with some arguing against mixing the two up and killing the debate on living wills. While euthanasia is legal in some countries, Singapore has banned euthanasia. There is strong public opinion against euthanasia with many arguing for better provision of palliative and hospice care to relieve the suffering of the terminally ill. Some questioned if underlying advance medical directives, as in euthanasia, is the bigger concern of the burden of cost imposed on the state and the family in caring for the infirm and terminally ill. There was concern that such measures devalue human life which should be preserved at all costs while others have come out to affirm their right to a dignified death, the definition of which is highly individualized. While adding to the debate, emotive arguments may detract from a more balanced perspective of advance care planning as a sensitive and patient centered process of reviewing a patient's wishes and values regarding the inevitable outcome at the end-of-life.

In the discussion of the process of advance care planning, other pitfalls have been identified, reflecting the complexity of the process. These include focusing the discussion too narrowly, for example on resuscitation status, unclear patient preferences and changes in values and preferences of patients over time. Patients who remain communicative while terminally ill may be ignored and the existence of advance directives may even misguide treatment. For example not all advance directives are for not aggressive treatment and should be read carefully.

Surrogate decision makers are integral role players in advance

care planning. Often but not always spouses or immediate family members, they are considered closest advocates to the patient who will help express and carry out the patient's preferences and last wishes. A pitfall is to leave the proxy decision maker out of the process of advance care planning discussion with the patient. As mentioned, it is important to involve the proxy decision maker at every step. In many cultures, the family is perceived to have the prerogative in making the final decision with regards to end of life care¹¹. In the paper on Attitudes and Preferences of Korean-American Older Adults and Caregivers on End-of Life Care by Kwak et al, a caregiver puts it this way; "After all, the final decision will be based on love and trust for each other rather than a legal document"¹¹.

On the other hand, caregivers have expressed a wish that their loved one complete an advance directive to facilitate decision-making. It should be recognized that surrogates do not always make decisions based on the patient's best interests or accurately predict patient preferences in specific scenarios. In guiding decisions regarding end of life, surrogates have described different motivators including knowledge gleaned from conversations with their loved ones, advance care directives, shared experience between themselves and their loved ones, the values and preferences of the surrogates themselves and enlisting the help of other people in the surrogates' network¹⁶.

Case 3

Madam CH was a 64-year-old Indian lady who suffered from diabetes mellitus, hypertension and end stage ischaemic cardiomyopathy. She has multiple admissions for congestive cardiac failure and in 2006, underwent implantation of an automatic implantable cardio defibrillator (AICD) for non sustained ventricular tachycardia. The AICD had discharged on a few occasions and while it brought her heart back to sinus rhythm, it usually caused physical pain for Madam CH. Madam CH has expressed her wish to the medical team that her AICD be switched off and that she be allowed to pass away in event of a malignant arrhythmia. However, her son, Mr S expressed strongly that he did not want the AICD to be de-activated. In conversations with Mr S, the palliative care team felt that Mr S was still coming to terms with the terminal nature of his mother's illness. The cardiology team complied with Mr S's wish not to de-activate the AICD as they felt Mr S might accuse them of prematurely withdrawing life saving treatment for Madam CH.

Madam CH's case illustrated that caregivers have different motivators in making end-of-life treatment decisions for their loved ones and may not always be centred around the patient's wishes.

While surrogates are not always perfect advocates for the patient, it is hoped that the close involvement of the proxy decision maker in the process of advance care planning will facilitate this.

Are the preferences of patients always associated with actual care at the end of life? Mdm CH's case in which her son refused to have her AICD de-activated reflected that this is not always so. When it comes to complex end of life decisions, physicians do not always make treatment decisions based on advance directives and are influenced by other factors such as the wishes of the patient's family, the patient's prognosis and the expected quality of life of the patient¹⁷. In an ironic twist, mismatches between patient preferences and end of life care can sometimes be found more frequently in cases where patients received less aggressive care than they desire¹⁸.

HOW DOES ONE INITIATE AND DISCUSS ADVANCE CARE PLANNING?

Many older adults and caregivers will want physicians to initiate and facilitate conversations regarding end of life¹¹. Most people would agree that advance care planning should be initiated when they are in stable health and not when they are actively dying or in times of crisis.

Many physicians may not be comfortable initiating advance care planning discussions. However, when sensitively discussed, it can facilitate rather than destroy hope¹². Advance care planning can refocus the aspirations of patients with regards to care and reduce the disparity between patients' expectations and reality.

The primary care doctor is well poised to initiate advance care planning with patients as a trusted physician who, ideally, knows the patient and his/her family. The primary care doctor also helps to co-ordinate the care of the patient. An outpatient clinic is a non threatening setting to discuss such matters.

In the United Kingdom, primary care practices receive guidance through the Gold Standards Framework programme on how to identify patients who might need supportive care, how to provide palliative care and how to initiate and perform advance care planning. Ideally, advance care planning should be routinely discussed with every adult patient in the practice regardless of age or present state of health.

As a start, one can take the opportunity to initiate advance care planning when the patient experiences the following events:

- 1) life changing event e.g. death of spouse
- 2) following a new diagnosis of life limiting condition
- 3) multiple hospital admissions
- 4) admission to a nursing home

Research has shown that the most successful measures that promote advance care planning in primary care included direct patient-healthcare professional interactions over multiple visits¹³. Use of printed materials without direct counseling was not as effective.

5 steps for successful advance care planning have been described¹

They are:

- Step 1 : Introduce the concept of advance care planning
- Step 2 : Explore and discuss with the patient his preferences and values
- Step 3 : Document what was discussed
- Step 4 : Review the subject with the patient on a regular basis and update the advance directives in case there is change
- Step 5 : Apply the directives to real situations.

Some questions that can be used to broach the topic are:

- 1) I'd like to talk to you about something I try to discuss with all of my patients. It's called advance care planning. Advance care planning will help both of us to understand your values and preferences for health care if you become seriously ill.
- 2) Can you tell me about your current illness and how you are feeling?
- 3) Who would you trust to make decisions for you should you become mentally incapacitated?
- 4) What fears or worries, if any do you have about the future?
- 5) In thinking about the future, have you thought about what is your preferred place of care as your illness gets worse?
- 6) What would give you the most comfort and meaning when your life draws to a close?

Discussion scripts and specific scenarios can be used to enhance understanding and reflection and to guide advance care planning. Involve proxy decision makers at the onset. In the discussion, it is essential to explain to the patient the meaning behind medical jargon for example what a "do not resuscitate" order is.

One should also explain the risks and benefits of different treatment options. A deeper discussion would explore the patient's values and preferences related to health and treatment in general and in specific situations. The patient's past experiences including with the people he/she knows will influence these values.

Case 4

Mdm L was a 75-year-old Chinese female who had a history of hypertension but was otherwise well. Previously, she cared for her husband who suffered from years of immobility following a stroke. She expressed her wish to her children that should she suffer from a condition that similarly immobilised her, she did not want her life to be prolonged artificially. One day she was admitted to the neurosurgical intensive care unit for a subdural haematoma sustained after an unwitnessed fall. The risks of operative risks were explained to her family and a decision was made for conservative management. She remained comatose and intubated after a few days of observation. Her children revealed to the medical team of her wish that extraordinary life support measures be withdrawn should she remain in a vegetative state. A decision was made to terminally extubate her and she passed away peacefully 2 days later.

Even though she had not previously discussed advance care plans with her physicians, Mdm L was able to express her wish with regards to end-of-life care to her children. There was a unanimous decision on the part of her family members to respect her wishes and withdraw extraordinary life support measures.

Documenting discussions on ACP

Within the National Healthcare Group cluster of healthcare institutions, an Advance Care Programme was started in 2008 to look after non-cancer patients who are terminally ill in the community. This programme endeavors to reduce the number of acute hospitalizations for such patients. Patients include those with renal failure who declined dialysis, advanced heart failure and end stage chronic obstructive airway disease. As part of the care for these patients, advance care planning is carried out in the form of an ACP document exploring the patient's preferences with regards to resuscitation status, place where they would like to be cared for and place of death. The outcomes of discussion are documented by the programme counselors on the document which is kept within the patient's file. The file will accompany the patient to any medical appointment or hospital.

Case 5

A patient within the programme, Mr T had Stage 4 chronic obstructive airway disease and was frequently admitted in hospital for exacerbation of his obstructive airway disease. Functionally, he was wheelchair bound, dependent on home oxygen therapy and required assistance with activities of daily living. During advance care planning discussions with Mr. T, he indicated his desire not to be intubated in case of respiratory arrest. He was admitted again for breathlessness and despite treatment with antibiotics, systemic steroids and regular nebulisations, his condition deteriorated over the next three days. He was commenced on a morphine infusion for palliation of his shortness of breath and passed away shortly after.

CONCLUSION

In conclusion, advance care planning serves the higher ideal of patient centered care at the end of life. It is a process, which is dynamic and highly individualized, and which cannot be reduced to the making of an advance directive. As a colleague of mine frames it:

"The advance medical directive is just a small part of advance care planning. I hope people will be more open to discuss about death and dying and think ahead of what they would want in the event of (physical) deterioration. Advance care planning should include preferences and extent of care, place of care, person to provide care, (preferred) place of death and resuscitation status."

Perhaps, besides respecting the choices of patients, the larger significance of advance care planning is its value in encouraging the individual to reflect on the brevity of one's life, to connect once again with what is important and to treasure every living day.

As Professor Morrie Schwartz said in his book *Tuesdays with Morrie*:

"It's when you learn to die, that you learn to live"

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