Definition

Advance care planning (ACP) is a process of discussion among the patient, care providers and relatives regarding the patient’s wishes, preferences, values and beliefs about future care to guide future best interests decisions in the event the patient has lost capacity to make decisions [1]. The discussion may lead to an advance statement (a statement of wishes and preferences), an advance decision to refuse treatment (an advance directive) in a pre-defined potential future situation, or the appointment of a surrogate to make decisions on the patient’s behalf.

Traditional versus developing model of ACP

The traditional model of ACP focused on completing an advance directive which allowed patients to prepare for incapacity and to have autonomy over what life sustaining treatments they would refuse when they lost capacity to make decisions. This would prevent doctors from imposing life-sustaining treatments on patients who might not want them. The ACP was usually discussed with the doctors or lawyers. However, the model of ACP has changed over the years. A study on the patients’ perspective regarding ACP showed that the patients’ purpose of ACP was to prepare for death and dying, and their underlying goals included the exercise of control and an attempt to relieve burdens placed on loved ones [2]. The process helped to strengthen relationships as it facilitated communication with their loved ones and so it was viewed more of a social process than just documenting an advance directive. The context usually involved close loved ones and doctors were involved only infrequently.

Facilitated ACP: The Respecting Choices Programme

Dr. Hammes quoted, “The Respecting Choices approach is not focused on the value of autonomy, forgoing treatment or the need for a specific document… It is focused on helping persons, in the context of their relationships, to explore and to discuss what it would mean to care about each other if a life-changing medical problem occurred.”
The programme is coordinated and systematic involving all healthcare providers within its district. Non-medical facilitators are trained to guide the patients and their relatives in the discussion process, such as nurses, social workers, chaplains and volunteers. The discussions are patient-centred and the family is usually involved. Their documentation is correctly filed and there is systematic staff education. They do not focus on death and dying which can be threatening for many but they talk about facilitating others to live well near the end of life.

During the process of ACP discussion, the patients need to understand what options and decisions that might be faced. They must be given ample time to reflect, discuss and communicate their issues, concerns and decisions with their care providers and family members their preferences must be clearly reflected in the documentation. The document needs to be retrievable and available when needed.

The Clients’ Perspective

Reflection on Personal Experience

As a cancer patient, I was offered some years ago to sign an advance directive. To this day, I still have not decided. In the AD form, what should I tick? There are so many hypothetical scenarios. I would have to discuss and decide on every possibility of how I might die which can be an emotionally draining exercise. Each circumstance is complex which would change over time. I anticipate my values and perceptions would also change. As life is full of uncertainties, it would be difficult to predict what I would want or would not want at a particular time and in a specific circumstance. There would be many variables in my decision-making process, for example, my physical and functional status at the time when I write my AD; my level of social support and psycho-spiritual status would determine my will to live or die, which would in turn affect my decision to want or refuse life-sustaining treatments. In addition, I would not only consider my wishes but my concept of self would also include the wishes of my loved ones. I would prefer my significant others and healthcare providers to know me as a person, to give me the opportunity to express my needs and share my wishes according to my pace, so when the time comes, I can be assured that they would act in my best interests, but perhaps this would be too unrealistic an expectation. Having experienced cancer, I have to embrace uncertainty and surrender to the reality that nothing ever goes as planned. Rather I need to focus on living in the here and now. I would prefer to think about my AD later when I am ready, and even when I am ready, I have to consider whether my loved ones are ready to discuss such death plans.

How do patients respond to ACP?

Some patients are not interested in ACP; some would discuss some but not specific aspects of future care [1]. The process may help them to focus their thoughts but it does not change their thinking. Their decision-making is based more on personal experiences with illness or witnessing of death and dying with preset beliefs rather than on information from healthcare professionals [4]. Some patients perceive ACP as a personal matter and would prefer to involve their loved ones rather than professionals in their discussion. The most significant factor revolves around the issue of not being a physical or emotional burden other than autonomy and control. Some may make a verbal statement only whereas others might document their wishes as an advance statement and AD to refuse life-sustaining treatments. They may appoint a surrogate to represent them who would act on their behalf in the event they have lost capacity to communicate or make decisions [1]. Some will review their wishes. One third of the patients will change their advance care plan over time, influenced by changes in diagnosis, hospitalization, health and functional status, social circumstances and mood [1].

Advance Care Planning: the Clients’ Perspectives
Potential Benefits, Harms and Risks of ACP

Existing data suggests that ACP is beneficial as it would allow the clients to prepare for death, have more realistic goal setting, have greater control over their dying process, and have their wishes documented and respected. Family members can participate in the process and be better informed of the disease, patient’s preferences and treatment options so that their burden of decision-making would be lessened, and their bereavement would be associated with less stress, anxiety and depression. The participation in the ACP would also strengthen family relationship as ACP is a social process. However, Randall has also pointed out the potential harms and risks of ACP [8].

Potential Risks

► The patient changes his mind but not the ACP. He may have updated his ACP form at home but not at the hospital.
► The patient may have misinformed choices or unrealistic expectations regarding his dying process.
► The Government has not estimated the resources needed to implement ACP. For example, if most patients prefer to die in a palliative care unit, there would be pressure to achieve the preferred place of death for these patients that there would be fewer beds available for other patients requiring symptom control. This would lead to ethically unjust allocation of resources.

Evidence-base data

Although previous research studies on the value of ACP and AD have been inconclusive, more recent studies have been more promising. Simon and Murray conducted a grounded theory study to explore the experience of end-stage renal failure patients who had completed facilitated ACP programme, adopted from the Respecting Choices Programme [4]. One must take into account that only six out of 18 patients agreed to participate in the study. Nevertheless, the participants viewed the process of ACP as a positive thing. Witnessing illness in self and others was a major factor which led them to think that they do not want to live in a state with physical or cognitive impairment. They perceived this quality of life as poor and that it would cause burden for themselves and their loved ones. The process of ACP gave them a peace of mind as it allowed them to address their concerns about living in a burdensome state for themselves and their families.

A recent Australian prospective randomized controlled trial studied the impact of ACP on end-of-life care in 309 elderly patients who were randomised to receive either usual care or facilitated ACP. Their reasons for hospital admission were mainly cardiac and respiratory diseases or falls rather than cancer. They were followed for six months or until death. Among the 56 patients who had died by six months, end of life wishes were much more likely to be known and respected in the patients who had been randomly assigned to receive ACP. They were more likely to be involved in EOL discussion. They were more satisfied with their hospital care in general as they felt they had received adequate information. They felt they were being listened to and were involved in decision-making. The surviving relatives’ stress level, anxiety or depression scores were less. 83% family in the ACP group was satisfied with the quality of death of the patients and 86% of them perceived that the patients would have been satisfied with their own death.

A recent American study looked at the association between preferences documented in advance directives and the outcomes of surrogate decision-making [6]. The medical records of 3746 descendants aged 60 years-old or above who had died during the period of 2000 – 2006 were reviewed. Of those patients, 42.5% required decision making, of whom 70.3% lacked decision-making capacity and 67.6% of those patients, in turn, had advance directives. Those who had prepared advance directives received care that was strongly associated with their preferences. Patients who had assigned a surrogate for health care were less likely to die in a hospital than those who had not surrogate to make decisions on their behalf. Another study showed that end-of-life discussions were associated with less aggressive medical care near death and earlier hospice referrals [7]. Aggressive care was associated with worse patient quality of life and worse bereavement adjustment.

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Potential Harms

- The discussion can be emotionally traumatic as it can be distressing to have to contemplate one’s dying in such detail. It is also difficult as the situations are only hypothetical. It may not be what the patient would want to hear.
- There can be conflict between the patient and relatives’ wishes, especially if the patient becomes mentally incompetent before the conflict has not been resolved.
- Relatives may not understand that the ACP is to record the patient’s wishes and preferences and not their perspective.
- The process is operator dependent and it must be led by a competent case manager.
- There can be political drive and doctors’ ideals to initiate the ACP which might not actually be in the patients’ best interests.
- There can be confidentiality issues as one cannot assume that the ACP / AD is open to all healthcare involved. Patient consent must be respected.
- There can be misapplication when the ACP is applied when the patient is still mentally competent.

Appropriateness in Initialing ACP

The potential harms and risks highlight the need for a coordinated programme and also trained facilitators who have the expertise in knowing where and when and how to initiate the discussion. Otherwise, one could turn a process which can potentially facilitate better communication, promote autonomy, control and peace of mind into an emotionally distressing experience with loss of hope, false promises and continual rumination on death.

Appropriate Setting

ACP discussion is not a single event but a process [1]. The surrounding should be comfortable and the consultation unhurried. It is better to take place during routine practice such as primary care or out-patient setting rather than in hospitals as patients tend to be more ill with pain, delirium or tiredness when hospitalized, and the hospital environment might cause undue influence on the patients to discuss ACP.

Appropriate Timing

Although most patients welcome the opportunity to discuss ACP and expect their doctors to initiate the discussion, ACP facilitators must exercise their professional judgment to gauge the appropriate timing to initiate the discussion, depending on the patients’ pattern of disease, prognosis, willingness and readiness to engage in such discussion. It should never be forced upon them [1]. Similarly, ACP discussions should not be continued if they are causing the patient excessive distress or anxiety.

Appropriate Client

ACP should be initiated in patients with long-term conditions or receiving end-of-life care. However, some patients with terminal disease or serious illness requiring hospitalization may not feel ready or able to do so [9]. ACP can also be initiated with clients who are stable but will anticipate future ill-health. ACP should not be initiated immediately after a move into a care home but only after the clients are more settled [1]. The clients must be mentally competent, and also have the time and energy to discuss and reflect on their wishes and preferences.
Art and Skills of a Facilitator

The ACP discussion is not a tick box exercise or a chart but an art. Not only must the ACP facilitators have the expertise and training in communication skills and how to discuss ACP, they must also know how to connect with their clients and come across as being trustworthy, and be empathic and intuitive to know when to initiate the discussion. Not only should they have knowledge about the disease trajectory, treatment options and prognosis, but they should also know their clients in their personal context, their preset beliefs and personal experiences. While it is important to inform, explain and clarify issues during the discussion, facilitators should also be aware of their coping mechanisms and the complex emotions that clients might be going through at the time. While helping the clients to set realistic goals and summarize their wishes and preferences, one must be aware of their psychosocial status and the possible QOL response shift. Facilitators must be sensitive to clients’ cues who may not want to discuss the ACP further; they should sensitively close the conversation so that the clients would not go home ruminating on death and dying.

Conclusion

In order for the process of ACP to be of value, a coordinated and systematic approach must be adopted with trained facilitators. The discussion is a social process that is patient-centred and includes family participation. Documentation is important, which can be in the form of a personal narrative to record the client’s wishes and preferences or an advance directive to refuse specific life sustaining treatment, the latter which is legally binding.

ACP is an art and facilitators must be aware of the clients’ personal context, their psychosocial status and personal beliefs. They require intuition to know the appropriateness of when and with whom to initiate the discussion and also be aware that the clients’ preferences would change over time, requiring regular review. Public education is important to ensure that clients are introduced to the concept early when they have the time, energy and feel non-threatened to think about such death plans according to their own pace.

References:
1. Concise guidance to good practice – advance care planning. www.rcplondon.ac.uk