Advance care planning in nephrology care

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Abstract
On completion of this continuing professional development (CPD) activity, participants will be able to:

• describe advanced care planning and its relationship to person-centred care
• identify who is responsible for initiating advance care planning discussions in their nephrology department
• identify the benefits of advanced care planning
• recall conversation triggers for raising the topic of advanced care planning.

“A continuously learning health system can deliver truly patient centred care only when patient preferences — informed by medical evidence and provider expertise — are elicited, integrated, and honoured.” (Alston et al., 2012, p. 3)

Keywords
Advance care planning, supportive care, nursing, kidney, education.

Introduction
Despite receiving substantial support within chronic and long-term health care settings, advance care planning (ACP) has yet to become fully embedded into routine clinical nephrology practice. This paper discusses ACP in the context of person-centred care, shared decision making, and self-determination. It identifies the benefits of ACP and suggests practical approaches to assist nephrology departments to provide a stimulus to start a conversation that matters and supports ACP discussions to become part of routine information provision and care for patients undergoing renal replacement therapy (RRT).

Historical perspective
‘Respecting Patient Choices’ was introduced into health care facilities in the Mid-Western United States (US) in the 1980s.

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After receiving significant public and governmental support, specific principles were enshrined into US law under the 1990 Patient Self Determination Act (PSDA) (Romer & Hammes, 2004). The philosophies behind the Act made their way to Austin Health in Australia in the early 1990s, and through support from State, Territory and Commonwealth Governments and were developed to become ACP, where the focus was on a person’s values, beliefs and quality of life choices rather than documentation of specific medical treatment choices in particular circumstances.

What is advance care planning?

ACP is a process that incorporates the principles of person-centred care, shared decision making, self-management and autonomy to support individuals to make plans for their future care. The process is initially reflective in nature and its philosophy is founded on personal beliefs, values, goals and preferences in life. Throughout this introspection the person identifies what is important to them and how this translates to clinical decision-making preferences in the event that they reach a point where they are unable to communicate decisions related to medical care independently (Victorian Government, 2015).

A note on terminology: terminology and legal standing of ACP documents varies across all states and territories of Australia. Advance care plans are also known as advance directives, advance care directives, statement of choices and living wills, all of which are legally binding in Australia, either at common law or under statutes. However, given that the purpose of an advance care plan is to allow people to clearly express their values and preferences to inform clinical decision making when they are too unwell to participate directly, due consideration needs to be given whatever form the document takes (Department of Health, 2014).

What are the benefits of ACP?

People with advance care plans formally documented are more likely to have end-of-life care wishes respected and are less likely to die in a hospital (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013). ACP discussion has also been shown to significantly reduce symptoms of post-traumatic stress, anxiety, and depression in family members (Detering, Hancock, & Reade, 2010). The reflective process of ACP affords the articulation of near- and long-term goals, and the opportunity for the individual to express any relationships between personal, cultural and spiritual views with potential clinical options. The philosophical tenets of person-centred care, including the promotion of dignity and respect, enables greater autonomy and decision making which, in turn, supports greater control over possible future events (Levi, Dellasega, Whitehead, & Green, 2010).

The process of creating an advance care plan may be informal or formal and should be undertaken while the individual is able to make informed decisions. The informal process of considering treatment options, and discussing them with significant others and care teams can identify what constitutes quality of life for a person. This discussion needs to include what would be considered an acceptable recovery after illness or injury and emphasise what is important to the person if they were nearing the end of their life. The outcome of the informal process should be that the person feels comfortable in the knowledge that they have had the right conversation with their nominated spokesperson, and are confident that their wishes are known and will be respected. The formal process, however, utilises a tool for directing patient-care provider communication through formal documentation of these discussions and choices. It involves identifying the person responsible for making health care decisions, and appointing an agent as an enduring power of attorney for medical treatment decisions as well as documenting relevant preferences and choices in an advance care plan. A simple way to assist both health professionals and patients to understand advance care planning formally, is an approach called “ACP in 3-steps”, developed by the Advance Care Planning Service at Northern Hospital, Victoria (Box 1).

| A: Appoint an Agent … A Medical Enduring Power of Attorney or a ‘Person Responsible’ for Medical Treatment decisions |
| C: Chat and Communicate … Talk to your family, friends and doctors about your health care preferences. What would you like doctors and others to know to help with future medical decisions? |
| P: Put it on Paper … If there is something you feel strongly about, write down preferences for future medical care |

Box 1: ACP in 3 Steps (NorthernHealth, 2013)

Why should ACP be part of routine nephrology care?

People undertaking RRT are likely to have multiple comorbidities that impact their quality of life, which adds layers of complexity to their social and medical care needs. There may be points during their disease trajectory where they experience a loss of decision-making capacity, suddenly or as an ongoing prolonged decline in cognitive and physical health. People will reach a point where decisions need to be made regarding the
One health care service experience
The Monash Health Advance Care Planning Service embarked on a re-framing awareness campaign for health professionals and consumers to promote and implement the ACP discussion in terms of planning for a time when there is a ‘loss of decision making’ rather than ‘planning for end of life’. This approach has resulted in both health professionals and patients being more willing to initiate a conversation regarding future health care wishes, and has seen overall referrals to the service increase by 518%, from 2014 compared to 2012.

A framework enabling routine embedding of ACP process is currently being formalised throughout Monash Health nephrology care settings, with the support of nurse practitioners, unit champions, nephrologists and the ACP office.

continuation of RRT (Josland, Brennan, Anastasiou, & Brown, 2012). The presence of an advance care plan will support individual wishes and the communication between the patient, person responsible and the nephrology team.

The who, how and when of ACP initiation: Having the conversation
In the first instance, there needs to be an organisation-wide focus on person-centred care for ACP to be successful. This also means having staff at all levels who are familiar with the aims and process of ACP. All Australian states and territories have some health department input into ACP processes that can be utilised as front-line resources. Furthermore, most major health care networks have ACP personnel who offer education and consultation to patient consumers and staff.

There is some debate and uncertainty as to who is responsible for initiating and discussing patients’ long-term care wishes, within the nephrology context (Davison, 2006). Primary care medical or general practitioners, specialty clinicians, social workers, nurses and nephrologists are all recommended; however, in reality, it is suggested that a collaborative approach works best (Scott, Mitchell, Reymond, & Daly 2013). Cultural differences aside, a Singaporean study on the perception of ACP in renal health care professionals for patients with end-stage kidney disease found that the frequency of ACP discussion was particularly low among nurses due to concerns about upsetting the patient, not seeing themselves as advocates for ACP and the preference to defer this role to the social worker or the nephrologist. However, nurses are ideally positioned to initiate the conversation due to the time spent with people on RRT and the positive rapport established as a result (Yee et al., 2011; Davison 2006).

Ideally, ACP discussions should take place when the person is medically stable, thinking clearly, comfortable and has had time to adjust to changes in their condition or prognosis (Department of Health, 2014). Introducing ACP within nephrology care environments early in the disease trajectory affords people the time to consider and reflect on their wishes and choices for future care. However, health care professionals are often reluctant or unsure of how to raise the topic (Josland, Brennan, Anastasiou, & Brown, 2012). Identifying potential key points along the care continuum for introduction, and being provided with useful phrases to introduce the ACP can be useful.

The palliative care paradigm suggests that the ideal time to initiate ACP discussions is up to 12 months prior to the commencement of dialysis, preferably during pre-dialysis education (Davison, 2006). This time is an integral part of the preparation for self-management and assists in informing the decisions made by patients and their carers (Fassett et al., 2011).

Other possible time-points include:

- Outpatient appointment after the patient has been provided with diagnosis and has had the opportunity to consider wishes and choices for future care.
- Routine renal education sessions.
- Nursing and social work assessments when commencing RRT.
- At any noticeable change in health and/or personal circumstances.
- Regular clinical or social review and assessments at RRT units.
- Use of the surprise question, “In light of all you know about this patient, would you be surprised if he/she was to die within the next 6 to 12 months?” — if the answer is “no”, then the conversation should happen sooner rather than later (Scott, Mitchell, Reymond, & Daly, 2013).

Helpful phrases that can assist in introducing ACP
The initial aim in initiating discussion is to describe simply and
clearly what ACP is, giving a rationale for why having these conversations can be helpful for the patient, families and the health care team. For example:

- “Have you thought about the type of medical care you would like to have if you ever became too sick to speak for yourself?”
- “Sometimes people with your type of illness lose the ability to make decisions or communicate their wishes as the illness progresses. Who would make decisions for you if you were unable to do this for yourself?”
- “Do you know who would make decisions about your medical treatment if you were unable to make them for yourself? Are you comfortable that this is the right person to speak for you?”
- “Have you spoken to the person who will make decisions for you? Would you like to include them in these discussions, so they know what is happening and what might happen in the future?”

The second point is to explain the mechanisms available for ACP within the patient’s health care service, state or jurisdiction:

- “Some people have thought about what they want and document their wishes in what is called an advance care plan. Have you done an advance care plan? I could get you some more information if you like, or refer you to someone who could explore this further with you.”
- “Would you like to complete one?” Adapted from Clayton et al., 2007.

Initiating and providing information to patients also requires a structured ACP framework to ensure the conversation is ongoing, plans are reviewed and are practically accessible when required. Such a process need not be complex, and within the unit it should be acknowledged that ACP is an important part of normal and routine nephrology care that incorporates a biopsychosocial approach. Introducing patients to some of the excellent, brief reading material already available — in the form of brochures — may be enough to instigate further interest from them, at which time they may be referred to an ACP professional. It is anticipated that this introduction can be as brief as 10 minutes or as long as half an hour — but documentation of the conversation should be properly integrated into the patient’s history in line with organisational process, to allow uptake from, or referral to ACP team members, and so that the information is flagged and readily available at a possible future time.

**Conclusion**

Embedding the ACP discussion into routine nephrology care...
requires a systematic approach, where the patient has the opportunity to be informed of processes that can support shared decision making, be given opportunity to consider their situation and either accept or decline an invitation to formally document choices for future care. Ongoing conversations and good communication systems will ensure a person’s choices for future care are available and accessible when required, along the length of their health care continuum. Nephrology nurses are well placed to initiate, support and refer the interested patient to formal ACP services.

References


