

PROMOTING PATIENT AUTONOMY AND COMMUNICATION THROUGH ADVANCE CARE PLANNING: A CHALLENGE FOR NURSES IN AUSTRALIA

Chris Shanley, MA RN, is Assistant Director, Centre for Education and Research on Ageing, Concord Hospital and Adjunct Senior Lecturer, Faculty of Health Sciences, University of Sydney, Australia

Sharon Wall, MPH, RN, is Director, Ageing by Caring, Coledale, Australia

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ABSTRACT

Many older people unable to give informed consent receive life-prolonging treatments in hospitals and nursing homes, even though these treatments may lead to a reduced quality of life and may not be consistent with what the people would choose if they could make their wishes known. Advance care planning provides an opportunity for a person to discuss and communicate their wishes about future care with significant others such as their family, treating doctor and other members of their health care team. Advance care planning has not been discussed explicitly in the Australian nursing literature. This article suggests that nurses can play a stronger role in promoting and facilitating advance care planning, through a number of roles consistent with mainstream nursing practice.

INTRODUCTION

Advance care planning (ACP) is a process of communication between a person and the person's family members, health care providers and important others about the kind of care the person would consider appropriate if the person cannot make their own wishes known in the future (Martin et al 2000). This would typically occur if the person develops dementia, suffers a severe cerebrovascular accident or becomes unconscious for whatever reason.

While ACP is directly linked to end-of-life treatment, the focus of this paper is on the process of developing advance care plans rather than on the management of end-of-life care, as in palliative care.

ACP is an important issue because many people will be in the situation of not being able to make decisions for themselves as they approach the end of their life. Advances in medical knowledge and life-sustaining technologies have meant that death has become a process or continuum in which life can be significantly prolonged (Schlenk 1997).

When asked, most people are clear that they would prefer to preserve a good quality of life rather than to have an extended life without regard to quality (Steinberg et al 1997; Miles et al 1996; Gamble et al 1991; Ebell et al 1990). However, there is no guarantee this will happen in the final stages of life. Decisions made to either aggressively treat illness and prolong life or undertreat illness will not always be consistent with what the person would have wished (Taylor and Cameron 2002; Haynorn 1998; Martin 1997; Perrin 1997). This is especially the case for people with cognitive or functional impairment who do not have family members who are able to advocate for them (Moody et al 2002; Meier 1997).

ACP brings end-of-life treatment out in the open and promotes an active communication over time about the issues between the patient, their loved ones and the health care team (Prendergast 2001; Martin et al 2000). This increases the chances that the persons' wishes will be understood and acted on when they cannot speak for themselves. It also lifts, from the family and healthcare staff, the burden of responsibility of having to make decisions for someone else when they are not sure what the person would want.

Nursing literature outside Australia has canvassed a range of issues to do with ACP and has suggested that nurses have an important role in promoting advance care planning for their patients (Feldt 2000; Sawchuk and Ross-Kerr 2000; Haynor 1998; Martin 1997; Parkman and Calfee 1997; Perrin 1997; Schlenk 1997; Johns 1996).

However, ACP is an issue that has had little attention within Australia in either the health care practice setting or literature. A review of the Australian health care literature on ACP and associated topics indicates a small number of articles in the medical (Taylor and Cameron 2002; Mador 2001; Hawkins and Cartwright 2000; Parker and Cartwright 1999; Waddell et al 1997; Waddell et al 1996) and social science (Cartwright 2000; Steinberg et al 1997) arenas.

After reviewing the published literature, Taylor and Cameron (2002, p.475) argue that 'the available evidence suggests that ACP in Australia has been poorly implemented and that many patients may remain disenfranchised in regard to their end-of-life medical management'.

Although nurses are managing end-of-life care as part of their core business, issues around ACP have not been explicitly addressed in the Australian nursing literature, with a scant number of references found (McLaughlin 2000; Cartwright et al 1997; Chiarella 1994). The aim of this paper is to promote reflection and discussion about the role of nurses in Australia in ACP. While the issues are relevant for all nurses, they are most relevant to those working with patients who have chronic and late stage illnesses.

The article will begin by providing background information on several legal mechanisms associated with ACP, including the current application of these mechanisms in Australia. The article will then propose a number of specific roles that nurses can play in promoting ACP amongst patients. These roles include communication facilitator, risk identifier, emotional supporter, advocate, healthcare agenda setter, educator and researcher.

LEGAL MECHANISMS ASSOCIATED WITH ADVANCE CARE PLANNING

Advance care directives

An advance care directive (ACD) is a document in which a person gives instructions about their future health care; it comes into effect only when the person is no longer capable of making their own decisions (NSW Committee on Ageing 1999). ACDs may also be referred to as 'living

wills'. Typically the directive is designed as a form with a series of questions about either core values or levels of treatment that the person would want under certain conditions. It is usually suggested that people complete these with their doctor and lodge copies with the doctor as well as close family members and their local hospital.

Much of the literature on ACD comes from the USA, where they are legally mandated. The Patient Self-Determination Act 1991 requires all publicly funded health services to inform patients about advance directives, honour the instructions in these directives, have clear policies and procedures to support this, and train staff and educate the public about advance directives (Parkman and Calfee 1997).

ACDs were promoted as a means of assuring that people's end-of-life wishes would be acknowledged and acted upon. Unfortunately, the early optimism about ACDs has not been reflected in the results of research on their effectiveness. A range of authors (Teno et al 1997; Perrin 1997; Miles et al 1996; High 1993; Danis et al 1991) have highlighted a number of limitations associated with ACDs:

- In spite of many people showing an interest in them, the majority of people do not go on to complete a directive.
- Forms may be unclear and ambiguous when it comes to making vital decisions about a person's care.
- Forms may become out of date as a person's health status changes.
- There is usually no system for storing and retrieving forms easily and consistently.
- Health care providers often do not recognise the legitimacy of the directives.
- There can be problems if family members do not agree with what is in the directive and want to overturn it.

Recently, several authors (Ditto et al 2001; Martin et al 2000; Teno et al 1998) have de-emphasised the importance of the written document and put a stronger focus on the processes of communication that occur as part of ACP. This change in approach to ACDs signals an important shift from a legalistic paradigm to a more holistic, patient-centred one.

Martin et al (2000, p.1673) suggest that '...an AD form is not the central or defining feature of ACP. ACP is a process of communication, and AD forms are best viewed as an assisting device embedded in the ACP process'. AD forms may help people to articulate their values, goals and preferences and can provide a framework to facilitate discussions with others. They can give structure and clarity to discussions about death, illness, and end-of-life care.

ACDs remain important but are neither necessary nor sufficient for successful ACP. They are helpful as a guide and facilitative mechanism to help patients, family and health care staff communicate openly about the issues. They are particularly useful if a person does not have a significant other who understands their wishes and is able to strongly advocate for them, or if they have quite specific wishes they want honoured.

Proxy decision makers

A second legal mechanism associated with ACP involves proxy decision makers - a person(s) recognised as being able to make decisions on your behalf if you are no longer able. Other terms used in this context may be advocate, guardian, or surrogate. In most situations, the closest family member(s) will be asked to make decisions on your behalf if you are not able. In the majority of cases, this is an appropriate approach as close family are the people most likely to know and respect the wishes of the patient (Martin et al 2000; Meier 1997; Perrin 1997).

Problems arise if there is no close family member and no identified proxy, if the proxy is not clear about what you would want, if the person is not easily available, if the person is afraid of making clear decisions or is unassertive about them, or if there is conflict within the family about the best way to proceed. Complications may arise if there are several people who want to make decisions on your behalf eg de facto partner and family members.

A useful strategy is to ask a patient 'Do you have someone that the health care system will easily recognise and accept as your proxy ('advocate' or 'guardian' may be more easily understood by some patients) and whom you are fully confident will make decisions that are based on what you would want?' If the answer is 'No' the patient can be helped to identify an appropriate person and make sure that person is willing and able to act as a proxy. There are legal systems - discussed below - for nominating a person(s) as your legal proxy decision maker.

It is ideal if the identified proxy is involved with the health care team during the person's illness rather than appearing only in a time of crisis (Teno et al 1998). It is important to choose an effective and available proxy and to make your wishes and values known clearly to that person. The proxy's role is not to make decisions based on their own values but to answer the important question 'What would my loved one decide if she/he could speak to us?'

Power of attorney

This concept - the third legal mechanism associated with ACP - will be familiar to most readers. It is a legal document in which a person appoints another person to manage their financial and legal affairs such as signing contracts. It might be used if a person becomes immobile and cannot get around easily.

Unfortunately, there are two widely held misunderstandings about Power of Attorney. The first of these is that having a Power of Attorney enables you to make any decisions for the person - including health care decisions. This is not the case as decisions are restricted to business, property and financial affairs (NSW Committee on Ageing 1999).

The second misunderstanding is that a normal Power of Attorney automatically lasts till the person dies. In fact, the Power of Attorney becomes invalid if the person who has given it subsequently develops dementia or otherwise becomes incompetent to make their own decisions. There is a specific type of Power of Attorney - usually called an Enduring Power of Attorney - that remains valid even after the person giving it becomes incompetent (NSW Committee on Ageing 1999).

Current status of these legal mechanisms in Australia

The landscape of ACP within Australia is complicated by each State having different legislative and health systems. Furthermore, advance care directives and proxy decision making are concepts that are not widely understood in the community or by health care professionals.

Power of Attorney is covered by a different Act in each State but these are fairly consistent. Systems covering proxy decision makers or guardians are not so consistent, although they all allow a person to nominate one or more others to make health care decisions on their behalf. The legal mechanisms under different State Acts include:

- Enduring Guardian (New South Wales and Tasmania)
- Enduring Power of Attorney for Personal/Health Matters (Queensland)
- Enduring Power of Attorney - Medical Treatment (Victoria)
- Medical Power of Attorney and Enduring Power of Guardianship (South Australia)

(NSW Committee on Ageing 1999).

The legal status of ACDs is even less clear. ACDs in some form are specified in legislation in the ACT, Queensland, South Australia and the Northern Territory (NSW Committee on Ageing 1999). There is some indirect reference in Acts or government regulations in New South Wales (NSW Health 1993) and Victoria (Cartwright 2000).

A common concern about ACDs is that they are not 'legal' and therefore the health care staff do not need to - and should not - follow them. However, in several States they are clearly legally recognised documents. In other States their power comes from a person's right in common law to determine their own health care - including the right to refuse treatment (Cartwright 2000; Parker and Cartwright 1999).

Information about legal mechanisms underlying advance care planning in each State can be found in a booklet 'Taking Charge: Making Decisions for Later Life' (NSW Committee on Ageing 1999) and in Cartwright (2000). Readers should be aware that legislation will continue to change in this area and that they need to keep updated about current legislation in their own State.

Apart from legislation, readers should also be aware of guidelines and other resources published in their State. Within New South Wales (NSW), for example, much work has been put in during 2001 and 2002 to revise the 'Guidelines for Decisions Making at the End of Life' by NSW Health. This is a comprehensive and practical document that is in final draft form at the time of writing.

NURSES' ROLES IN ADVANCE CARE PLANNING

ACP can provide positive outcomes for both patients and their family carers. They can help people prepare for death by giving patients a sense of control, relieving burdens on loved ones, and strengthening or reaching closure in relationships with loved ones (Martin et al 2000). 'Research does show that advance planning catalyses important, memorable, and therapeutic discussions between patients, providers and family members about emotionally and conceptually difficult issues' (Miles et al 1996, p.1066).

The non-Australian nursing literature has put forward a number of roles that nurses can play in promoting and facilitating advance care planning (Jacobson 2000; Haynor 1998; Martin 1997; Parkman and Calfee 1997; Perrin 1997; Schlenk 1997; Johns 1996; Mezey et al 1996).

Johns (1996) suggests that nurses have roles in facilitating the initiation of advance directives, integrating family members as surrogates and advocating for patients to ensure their treatment choices are respected. According to Haynor (1998), nurses' roles in ACP include the giving of information and provision of emotional support to the patient and their family.

Perrin (1997) suggests that nurses have several roles in ACP. These include preparing people to think about end-of-life decision-making for themselves and their family members, providing public education about end-of-life decision-making, and facilitation of discussions about a person's end-of-life wishes within the health care team. Jacobson (2000) suggests that nurses are ideally placed to introduce the patient to the importance of ADs, to monitor how treatments comply with patients' preferences, to facilitate discussions amongst family members and to develop a dialogue about end-of-life care between those in the facility who make ethical recommendations and those who carry them out at the bedside.

As pointed out earlier in this paper, ACP is an area that has not been explicitly addressed in the Australian nursing literature. On the basis of the benefits of ACP and the range of suggestions from the broader nursing literature,

we believe that nurses in Australia need to take a greater role in promoting and facilitating ACP as an important aspect of nursing practice.

Two factors will assist nurses to move in this direction. The first is to become well versed in medico-legal concepts such as consent and decisional capacity (Darzins et al 2000; Molloy et al 1999) as well as the legal frameworks surrounding ACP in their State (Des Rosiers and Navin 1997; Schlenk 1997).

The second factor is to become aware of and work through their own issues and feelings about death and dying (Schlenk 1997). Discussing death and dying is difficult for most people. It will be made easier if the nurse feels comfortable to raise and discuss the issues. Nurses can help each other in this regard through peer support, education programs and clinical supervision.

We propose a number of roles that nurses can play in promoting and facilitating ACP. These proposed roles are based on an analysis of the literature and our own sense of sound nursing practice. The roles are as communication facilitator, risk identifier, emotional supporter, advocate, health care agenda setter, educator and researcher.

Communication facilitator

Of all health care workers, nurses spend the most amount of time with patients. Their relationships are more intimate and more holistic. Patients want to discuss end-of-life care but prefer health care workers to initiate discussion about this (Johns 1996; Mezey et al 1996). Nurses are ideally placed to initiate this discussion because of the openness and trust that often characterise their relationships with patients.

Nurses often also develop close relationships with the family of patients - especially if they are in a long-term caring situation. Because they can understand issues from the patients' and families' perspectives they can often facilitate discussion that the family may find difficult to initiate (Johns 1996). The nurse has a pivotal role in promoting communication about advance care planning amongst the patient, family, treating doctor and other members of the health care team.

Communication about end-of-life care should be a routine aspect of care for all patients - particularly those with chronic and late stage illnesses. It should not be left until just before the person dies.

Risk identifier

Nurses can be attuned to patients that are more likely to have problems in their end-of-life care. It may be helpful for nurses to ask all their patients the question mentioned earlier in this paper: 'Do you have someone that the health care system will easily recognise and accept as your proxy (or advocate) and whom you are fully confident will make decisions that are based on what you would want?'

In many cases, the person will have a supportive family whom they are confident will make wise decisions on their behalf (Martin et al 2000; Meier 1997; Perrin 1997). However, if the person answers 'No' to the question, the nurse can help in several ways. They can encourage the patient to write down issues that will be important to them in the way they are cared for toward the end of their life; they can suggest the patient discuss these issues fully with their treating doctor; and they can assist the patient to select and nominate an appropriate proxy decision-maker and then discuss these issues with that person as well.

Emotional supporter for patient and family

Problems can arise if family members have difficulty accepting the death of a loved one. They may find it hard to accept that more cannot be done to prolong life. On the other hand, they may be distressed that the person is suffering and want their death to come more quickly. This is made worse if the wishes of the family are at odds with what the patient has expressed or if there is conflict between family members about the best course of action.

The nurse can liaise with the treating doctor to ensure that the patient and family have sufficient medical information and support. The nurse can help by conducting private conferences, providing additional diagnostic information, encouraging open family discussions, providing time and emotional support to family members and arranging religious and counselling support as appropriate (Haynor 1998). Family members should be fully informed and actively involved in direct patient care as appropriate. When the patient is no longer able to make decisions, the nurse can support the family by helping them work through the care options and make decisions based on the best interests of the patient.

Advocate

Respect for personal autonomy is one of the core principles of both nursing philosophy and practice. For nurses to truly apply this principle they must be prepared to advocate for a patient whose wishes they think are not being respected.

'This conviction that the patient's autonomy should be respected brings with it, however, a particular requirement: that of exercising the role of advocacy. This role can take different forms: informing patients of their rights; ensuring that patients have all the information necessary to make enlightened choices; supporting patients in their decisions; and protecting patients' interests' (Blondeau et al 2000, p.407).

Johns (1996) suggests that nurses, because of their insights into patients' preferences and their role as patient advocates, have a legitimate role in ensuring that treatment complies with patients' preferences - as expressed in their advance directives. At times this may require the nurse to challenge the treatment proposed by other members of the health care team. The role of

advocate may also be to speak on behalf of family members who are not being given enough information or are not being fully consulted about treatment plans.

Health care agenda setter

While advance care planning is an important part of sound nursing care, it is not an issue confined to nursing, and nurses can play an important leadership role promoting the issues within the wider health system.

This might include raising the issues with those parts of their organisation that are responsible for ethical issues and quality improvement, with a view to incorporating ACP into the organisation's systems and procedures. Discussion of ACP can be included as a routine part of case conferences. It can be included in orientation, in-service and grand round presentations.

Nurses can also promote ACP within their profession. This might be through presenting papers at nursing conferences, providing case reports and articles for journals and incorporating issues into nursing curricula.

However, the promotion of ACP should not only depend on the personal enthusiasm and motivation of nurses. It is vital that it be taken up as an organisational responsibility. This will make it more likely that appropriate care practices will be adopted across the whole organisation on a longer-term basis.

Educator

The nurse has two types of educative roles. One is with patients, family members and the general community. The other role is in education of other nurses and health care providers.

In terms of the first of these roles, the best time for patient education is not in the emergency department in the middle of a crisis. It is more appropriate in a primary health care or community setting. Education about advance care planning should emphasise the benefits of communicating beliefs and values with family members and health care providers while the person is still healthy and competent.

A collaborative approach working through seniors' organisations, religious and volunteer groups is a useful way to go (Haynor 1998). Information could be provided through a range of media - including one to one interventions, seminars, print and audiovisual resources. Information could also be channeled through existing information services aimed at seniors and the general public (Sawchuk and Ross-Kerr 2000).

In terms of the second educative role, education of nurses and other health care staff will increase their understanding and comfort level when promoting ACP. Education programs need to go beyond simply imparting information. Nurses need to develop skills in raising and discussing these issues with patients and their family members. They need to be able to assess decisional capacity to execute an advance care directive and identify

methods to help patients and family work through the range of choices available to them (Darzins et al 2000; Mezey et al 2000; Molloy et al 1999).

For advance care planning to become a more explicit aspect of nursing practice, comprehensive education programs addressing the issue would need to be developed and fed into both workplace learning and academic curricula (Des Rossiers and Navin 1997). These authors suggest that educational programs should address the following issues: patient autonomy, cultural sensitivity, family support, legal implications, health and psychological effects and ethical considerations (Des Rossiers and Navin 1997).

Researcher

There are many issues that nurse researchers can focus on to gain a better understanding of, and further promote, the practice of advance care planning (Haynor 1998; Johns 1996). These include:

- nurses' knowledge and attitude to advance care planning;
- patients' preferences regarding the roles of nurses in advance care planning;
- best times and strategies for implementing advance care planning;
- the role of cultural and language background in advance care planning;
- effective ways to educate all the stakeholders about advance care planning;
- the relationship between a written directive and a well informed proxy;
- potential ethical conflicts between patient autonomy and some nurses' perceived responsibility to prolong life; and,
- nurses' roles in advance care planning in relation to the roles of doctors and other health professionals.

CONCLUSION

End-of-life care is an area of increasing clinical and ethical complexity. This is because of the ageing of the population and the technology that is available and promoted to prolong life even when the consequent quality of life is poor.

ACP is one effective response to this complexity. It allows people to openly discuss how they would want end-of-life decisions to be made on their behalf.

Discussions with close family members or loved ones, the treating doctor and other significant members of the person's healthcare team will provide a greater sense of autonomy and security for the person at the centre of the discussion. They will also mean that all parties will be

more clear and confident about implementing the person's wishes when the person can no longer express them.

ACDs are written statements of a person's values and wishes relevant to their end-of-life care. They are a tool to initiate and facilitate discussion between a patient, family members and health care staff. By promoting and respecting ACDs, health care staff contribute to autonomy in decision-making by their patients.

Family members can be supported to become effective advocates for their loved one. In situations where there is not a clear advocate in the picture, the person can be assisted to select and nominate a guardian within the local legal framework.

While nurses are intimately involved in providing end-of-life care, ACP has not been addressed as an issue in its own right within the Australian nursing literature. Because of their close connection with patients and family members, their advanced communication skills and their philosophical commitment to patient autonomy, nurses can take a more explicit and active role in promoting the importance of ACP. Specific roles they can play in this regard are as communication facilitator, risk identifier, emotional supporter, advocate, healthcare agenda setter, educator and researcher.

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