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ADVANCE DIRECTIVES: THE NURSE'S ROLE

INTRODUCTION

Persons receiving health care often worry that if they become incompetent and unable to express their wishes, they will be subjected to treatments and interventions they do not want. Advance directives have been suggested as one way to address this problem, and in 1994 the Canadian Nurses Association (CNA), along with several co-sponsors concerned with ethical issues in health care, produced a *Joint Statement on Advance Directives* to facilitate their use in practice. While the use of advance directives is becoming more common, the ethical and legal responsibilities of the registered nurse* caring for clients making end-of-life decisions are not always clear. This paper provides an overview of advance directives and their associated advantages and limitations, the nurse's role regarding advance directives, and a discussion of how CNA's *Code of Ethics for Registered Nurses* can guide nurses dealing with the issue. A case study also illustrates how advance directives relate to a nursing practice situation.

WHAT ARE ADVANCE DIRECTIVES?

Advance directives refer to the means used to document and communicate a person's preferences regarding life-sustaining treatment in the event that they become incapable of expressing those wishes for themselves. Advance directives may take two forms: an *instruction directive*, commonly referred to as a living will, which details what life-sustaining treatments a person would want or not want in given situations; or a *proxy directive*, which explains who is to make health care decisions if the person becomes incompetent. A proxy** directive is frequently referred to as a power of attorney for personal care.

It is necessary for nurses to be aware of the legal status of both types of advance directives in their province or territory. Some provinces and territories recognize only *proxy directives* as legally binding, while others recognize both *proxy* and *instructional*

* In this paper nurse means registered nurse.

** Proxy is a legal term often used to designate a substitute decision-maker. For the purpose of this paper, the two terms are used interchangeably.

directives. In addition to knowing the laws regarding advance directives, nurses should also be familiar with provincial or territorial law regarding a person's competence to consent to treatment as this matter is closely related to advance directives. Advance directives come in many formats, and the version used may vary depending on the region of the country. Most formal advance directives allow people to specify the kinds of interventions they would want, given different levels of health and potential treatment circumstances. For example, CPR is one specific treatment people are often asked to consider in personal care directives. CPR decisions are frequently guided by consideration of whether the person's condition is reversible/irreversible or tolerable/intolerable. The pamphlet *Making Decisions About CPR*, identifies issues that should be considered.

Another advance directive that is commonly used is the University of Toronto Centre for Bioethics *Living Will*, which has been translated into a number of different languages and has been adapted for people with HIV/AIDS and cancer.¹

As a result of the client's decisions, outlined in formal advance directives, the physician responsible may write a do-not-resuscitate order (DNR) on the client's health record. Nurses are encouraged to consult the document by CNA and others entitled, *Joint Statement on Resuscitative Interventions*, for more guidance. Health care providers should know the client's wishes about resuscitation because this knowledge is needed in circumstances where the client is unable to indicate consent or non-consent.

There is a tendency, in both the literature and in practice, to focus on the "paperwork" that makes up an advance directive or on the issue of whether a specific advance directive document is legal. It is important, however, to see advance directives as part of an on-going process of communication between clients, or their substitute decision-makers, and health care providers. A significant part of this process involves obtaining a statement of personal values. A "narrative inquiry" can be used to identify and document the value system of the individual and his/her beliefs about well-being. Nurses may want to research other methods of gaining and recording information about a client's values or a "values history" that can be incorporated into an advance directive.²

THE ADVANTAGES AND LIMITATIONS OF ADVANCE DIRECTIVES

While advance directives are widely promoted in today's society, nurses should be aware of some of their advantages and limitations.



Advantages of advance directives

One of the primary purposes of advance directives is to support individuals in making decisions on their own behalf, thereby promoting the principle of self-determination. Advance directives promote fair treatment of incompetent individuals by providing a mechanism through which prior wishes regarding life-sustaining treatment can be communicated. Advance directives also reduce the difficulties faced by the loved ones and caregivers of an individual in a life-threatening situation, by providing guidance that is in keeping with the wishes of the client. Such directives help to reduce or resolve disagreements between clients and their families. Practitioner-client communication is enhanced through the use of advance directives by providing a focus for the discussion of significant issues around end-of-life treatment decisions.³

Limitations of advance directives

One of the main arguments against advance directives is that written documents may be vague and difficult to apply in a specific clinical situation. For example, a person might specify that they do not want *anything* done to prolong their life. Are they referring to the use of antibiotics and fluid and nutrition? Or are they referring to more “extreme” interventions such as intubation and ventilation or defibrillation?

Advance directives may lead to inappropriate treatment decisions if situations arise that a person could not foresee or consider at the time of writing the directive. For example, when the advance directive is being applied, a previously requested treatment may be of no benefit. Or, the inverse may occur if a person refuses a future treatment option based on the understanding that the situation would be hopeless, and the circumstances then take an unexpected turn for the better. Clients may also change their mind regarding the type of treatment they want but forget to change their advance directive. This could result in the client receiving treatment against his/her will.

Unfortunately, the focus of end-of-life decisions is often technology (e.g., withdrawal of treatment), rather than the goals of care (e.g., palliative care rather than restorative care). Another inherent problem is that most advance directives documents use language that is biased toward refusal of treatment. This bias is problematic for two reasons. It might be incorrectly assumed that if a person has not completed an advance directive, they want all life-sustaining treatment provided to them. Conversely, if a client indicates all the types of care they do not want to receive, rarely is there any discussion of the care they will continue to receive despite the fact that they have refused certain life-sustaining treatments. There is often too little focus on the goals of care for the individual and how these goals will be reconsidered as they change over days, weeks, or months of failing health.⁴

THE NURSE'S ROLE IN ADVANCE DIRECTIVES

Supporting client decision-making

In day-to-day practice, and in a variety of settings, helping clients plan for their future treatment through the use of an advance directive may be the responsibility of nurses as part of the health

care team.⁵ Nurses are well suited to facilitate the initiation of advance directives because of their unique relationship with clients and families.

The first step in supporting clients who are considering end-of-life decisions should be for nurses to reflect on their own beliefs and values associated with these issues and to be comfortable with them. Nurses should also be informed about advance directives, about the ethics of treatment at the end-of-life, about the client's medical and nursing care status, and about the sociodemographic characteristics of the client and his/her family that might influence decision-making. An example of a situation where these considerations are significant is that of an elderly patient who signs a directive declining all treatment because he does not have family members who can provide support to him.

A second step for the nurse is to enter into discussions with clients to help them clarify their values, beliefs, and understanding of themselves in the context of their current situation. The nurse then teaches how to express all of these ideas and wishes in a living will and explains how to appoint a substitute decision-maker. The *Joint Statement on Advance Directives* can also provide guidance in discussing advance directives with clients.

INTERPRETING AND FOLLOWING THROUGH WITH THE CLIENT'S WISHES

Another role related to advance directives is nurses' responsibility as client advocates, and their understanding of client preferences. Nurses in most provinces are legally bound to ensure that treatment is consistent with the client's wishes as expressed in the advance directive. It is also critical to remember that written advance directives are not always used in practice. The nurse's role may be instrumental in ensuring effective communication of the client's treatment wishes, and the presence and content of an advance directive, to the other members of the health care team. This may include alerting others to a change in the client's wishes, or advocating on behalf of the client or substitute decision-maker in situations where the client's wishes or advance directive are not being followed.

WHAT GUIDANCE DOES THE CODE OF ETHICS FOR REGISTERED NURSES PROVIDE?

Two of the functions of *The Code of Ethics for Registered Nurses* relate to the nurse's role in advance directives. The code serves as a means for reflection on ethical nursing practice, thus guiding nurses who are involved in coaching or teaching clients about advance directives. Also, because the code provides guidance for decision-making concerning ethical matters, it applies in situations where the nurse is ensuring that a client's advance directive is respected and implemented. The code identifies values and associated responsibility statements that clarify the application of the values and provide more direct guidance. Three values are particularly relevant to the nurse assisting clients with end-of-life decision-making, they include: 1) health and well-being, 2) choice, and 3) dignity.

1. Health and well-being

The highlighted responsibility statements related to this value emphasize the nurse’s accountability to the client for addressing the institutional, social and political factors that impact health care. Nurses fulfill this responsibility by ensuring that the institution in which they work has a policy regarding advance directives, or at another level, by lobbying the provincial government to ensure that the legal status of advance directives is addressed.

The second highlighted responsibility statement guides the nurse’s actions in supporting a client’s dignified life and death. Nurses help to meet this responsibility by ensuring that a client’s wishes, as expressed in an advance directive, are respected, and by continuing to provide care and support even when life-sustaining treatments are discontinued.

2. Choice

The value of choice is very relevant in describing the nurse’s role regarding advance directives. Nurses foster the process of advance directives by providing education, promoting the exploration and identification of values, and documenting clients’ expressed wishes. While nurses seek to involve clients in the process of health care decision-making, they must be mindful of their own personal values and potential value conflicts.

The third identified responsibility statement related to the value of choice and the nurse’s role regarding advance directives concerns

respecting a client’s health care choices. Nurses are responsible for respecting any legally appropriate client wishes that were made known prior to the client becoming incompetent. If nurses are in a practice situation where they know a client’s expressed wishes are being disregarded, they may seek specific guidance on page 26 of the code, which outlines steps that a nurse can take to address unsafe and unethical care.

A fourth responsibility statement provides guidance in situations where care decisions may not have been outlined in an advance directive and the nurse must obtain consent from a substitute decision-maker. It is the nurse’s responsibility to treat the family with the same respect that is normally given to the individual client.

3. Dignity

Keeping in mind the value of dignity, it is essential that nurses take into account the numerous biological, psychological, social, cultural and spiritual considerations that have an impact on end-of-life treatment decisions, and advocate on behalf of the client to ensure that these factors are made known to substitute decision-makers and other caregivers.

Advance directives are tools that nurses use to ensure that the client’s values regarding quality of life are communicated and that decisions about life-sustaining treatment are based on these values. Given that many life-sustaining treatments are closely linked to technology, it is essential that the nurse respect client wishes regarding such interventions.

VALUE	DESCRIPTION OF VALUE	ASSOCIATED RESPONSIBILITY STATEMENTS
HEALTH AND WELL-BEING	Nurses value health and well-being and assist persons to achieve their optimum level of health in situations of normal health, illness, injury, or in the process of dying.	<p>“...nurses are accountable for addressing institutional, social and political factors influencing health and health care.” (p.8)</p> <p>“Nurses foster well-being when life can no longer be sustained, by alleviating suffering and supporting a dignified and peaceful death.” (p.9)</p>
CHOICE	Nurses respect and promote the autonomy of clients and help them to express their health needs, and values and to obtain appropriate information and services.	<p>“Nurses seek to involve clients in health planning and health care decision-making.” (p.10)</p> <p>“Nurses are sufficiently clear about personal values to recognize and deal appropriately with potential value conflicts.” (p.11)</p> <p>“Nurses respect decisions and lawful directives, written or verbal, about present and future health care choices affirmed by a client prior to becoming incompetent.” (p.12)</p> <p>“Nurses seek to obtain consent for nursing care from a substitute decision-maker when clients lack the capacity to make decisions about their care....” (p.12)</p>
DIGNITY	Nurses value and advocate the dignity and self-respect of human beings.	<p>“Nurses exhibit sensitivity to the client’s individual needs, values, and choices.” (p.13)</p> <p>“Nurses treat human life as precious and worthy of respect. Respect includes seeking out and honouring clients’ wishes regarding quality of life.” (p.13)</p> <p>“Nurses advocate the dignity of clients in the use of technology in the health care setting.” (p.14)</p>

CASE STUDY

Based on the description of advance directives and an overview of how The Code of Ethics for Registered Nurses guides nurses in the care of a client considering end-of-life treatment decisions, consider the following case study and reflect on the questions asked. It may be useful to discuss the case with a colleague and to consult documentation regarding advance directives from provincial or territorial professional associations. As well, Everyday Ethics: Putting the Code into Practice, a study guide for the The Code of Ethics for Registered Nurses offers some tools to help nurses consider ethical dilemmas.

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Mr. Allan, 67, suffers from end-stage cardiac failure, and has been hospitalized for a week. During this time, his primary nurse, Kate, and his physician, have gently, but insistently, begun to discuss with Mr. Allan and his family his preferences regarding end-of-life treatment decisions. Kate and Mr. Allan talk about what is most important to him in his life. Mr. Allan tells Kate that he is not ready to die and he is afraid to die, however, he does not want to be kept alive if his quality of life is not likely to improve. He does not want to live like an invalid and be a burden to his family.

After this extensive discussion of Mr. Allan’s values, he decides what treatments he would want in the event that his condition further deteriorates. After Kate describes the specifics of what is involved in resuscitation, Mr. Allan decides that he would not want CPR or intubation and treatment with a ventilator. He decides that he would accept IV fluids if he were unable to eat or drink since he would not want to starve to death. However, he would not want a feeding tube. Although his wife and son are very upset about the possibility of Mr. Allan’s imminent death, they respect his

decisions. Mr. Allan's wishes are documented on his chart, and the physician signs a DNR order. Given that Mr. Allan's prognosis is so limited, and the fact that the family seems quite aware of, and supportive of his wishes, they do not take the time to complete an actual "living will" document.

Questions to consider:

1. What other issues might have been addressed with Mr. Allan as he considers end-of-life decisions?
2. What actions might Kate have taken if there had not been consensus among the family or the members of the health care team regarding Mr. Allan's care?

The next evening, Mr. Allan's daughter, Pat, who lives in another province, arrives to find her father barely conscious. She is understandably upset and asks her mother why the health care team is not doing more to help her father. Mrs. Allan explains to her daughter the decisions that her father made earlier that week. Pat is angry with her mother and brother, and questions their motives for supporting her father's decision to "give up." She quickly convinces her family to instruct the health care team to do everything possible to prolong Mr. Allan's life.

After some discussion, the physician on-call reluctantly reverses the DNR order, because of his fears of going against the family's wishes. Kate arrives the next day facing the news of the changed situation. She dreads the prospect of Mr. Allan having a cardiac arrest during the course of her shift.

More questions to consider:

1. What ethical and legal dilemmas is Kate facing?
2. What guidance could *The Code of Ethics for Registered Nurses* provide for Kate as she begins to address this situation?
3. What would be appropriate actions for Kate to take next?
4. What things might have been done to prevent this situation from occurring?
5. What if Kate had been starting a night shift? How might the situation be different?

CONCLUSION

This paper describes some of the current issues surrounding the use of advance directives and the nurse's role regarding their use. It is intended to be used as a complementary tool to *The Code of Ethics for Registered Nurses*. In addition to these resources, the nurse is encouraged to turn to resources in the practice environment. Nursing colleagues, other health professionals, management, and ethics committees, as well as the provincial/territorial nursing associations can be helpful in supporting the nurse's ethical commitment to client choice and dignity in increasingly challenging practice situations.

CNA REFERENCES:

Canadian Nurses Association. (1998). *Everyday ethics: Putting the code into practice*. Ottawa: CNA.
Canadian Nurses Association. (1997). *The code of ethics for registered nurses*. Ottawa: CNA.

Canadian Health Care Association, Canadian Medical Association, Canadian Nurses Association, Canadian Catholic Health Association of Canada. (1996). *Making decisions about CPR: Cardiopulmonary resuscitation*. Ottawa: Authors.
Canadian Health Care Association, Canadian Medical Association, Canadian Nurses Association, Canadian Catholic Health Association of Canada in association with the Canadian Bar Association. (1995). *Policy statement: Joint statement on resuscitative interventions*. Ottawa: Authors.
Canadian Nurses Association. (1994). *A question of respect: Nurses and end-of-life treatment dilemmas, A brief to the special senate committee on euthanasia and assisted suicide*. Ottawa: CNA.
Canadian Home Care Association, Canadian Hospital Association, Canadian Long Term Care Association, Canadian Nurses Association, Canadian Public Health Association, Home Support Canada. (1994). *Policy statement: Joint statement on advance directives*. Ottawa: Authors.

ADDITIONAL REFERENCES:

1. Molloy, W. & Mepham, V. (1996). *Let me decide*. Toronto, ON: Penguin Books; University of Toronto Joint Centre for Bioethics. (1997); Singer, Peter A. *Living will*. [On-line]. Available: <http://www.utoronto.ca/jcb> also available on videocassette 20 min.
2. Doukas, D.J. & McCullough, L.B. (1991). The values history: The evaluation of the patient's values and advance directives. *The Journal of Family Practice*, 32(2), 145-153; Grundstein-Amado, R. (1992). Narrative inquiry: A method for eliciting advance health care directives. *Humane Medicine*, 8(1), 31-39; Lambert, P., McIver Gibson, J. & Nathanson, P. (1990). The values history: An innovation in surrogate medical decision-making. *Law, Medicine and Health Care*, 18(3), 204-212; Singer, P. (1994). Advance directives in palliative care. *Journal of Palliative Care*, 10(3), 11-116.
3. Kelner, M., Bourgeault, I.L., Hebert, P.C. & Dunn, E.V. (1993). Advance directives: The views of health care professionals. *Canadian Medical Association Journal*, 148(8), 1331- 1338.
4. Advance Directives Seminar Group, University of Toronto Joint Centre for Bioethics. (1992). Advance directives: Are they an advance? *Canadian Medical Association Journal*, 146(2), 127-134.
5. Earle, C.J. (1992). Nurses' role in advance directives. In *Ethics in the new age* (Vol. 1), edited by V. Bergum, A. Schweitzer & J.B. Dossetor. Edmonton, AB: University of Alberta; Johns, J.L. (1996). Advance directives and opportunities for nurses. *Image: Journal of Nursing Scholarship*, 28(2), 149-153; Storch, J.L. & Dossetor, J. (1994). Public attitudes toward end-of-life treatment decisions: Implications for nurse clinicians and nurse administrators. *Canadian Journal of Nursing Administration*, 7(3), 65-89.

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