



REGIONAL GERIATRIC PROGRAMS OF ONTARIO

Introduction:

A review of recent literature on Advance Directives illustrates primarily that there are benefits and limitations to the use of Advance Directives and, most importantly, that advance directives are valuable when used as a communication tool for family, physicians and other healthcare providers to have a common understanding of what the person receiving care would like to happen at the end of his/her life.

Legal aspects:

The literature would support that Advance Directives are legally binding documents when completed by a person who is capable (Ontario Guide to Advance Care Planning, 2000); the literature regarding the legal status of Advance Directives once a person is incapable is somewhat less clear. Health professionals should use the directive as a guide but must clarify the treatment preferences of the patients or substitute decision-maker (SDM) as part of developing the management plan. In circumstances where the patient has an advance directive but is unable to participate in this clarification, the substitute decision-maker is expected to act according to the patient's previously stated wishes. If they ask for treatments that appear to conflict with the content and implications of the advance directive, clinicians need to ensure the SDM is acting in the patient's best interest.

There are no Canadian laws encouraging or requiring hospitals, LTC facilities or practitioners to educate patients about advance directives (Hoffman 1997). There is a consensus in the literature regarding the need to increase efforts to provide informative programs about advance directives to the public and to members of health care professions.

Advance Directives in the community setting

Approximately 12% of Ontarians and 10% of Canadians have completed an advance directive form. (Singer 1996;Hamel 2002) There is strong public support (90%) for preparation of Advance Directives and strong interest (84%) in learning about all possible outcomes of illness so that treatment decisions can be reached (Storch 1998). Both the Canadian Nurses Association (CNA) and the Canadian Medical Association (CMA) support the concept of Advance Directives. Some hospitals and LTC facilities have policies regarding the use of Advance Directives, some have developed their own advance directive forms. Advance

Directives are usually viewed in a positive light by physicians and patients: 85% of physicians in Ontario favored the use of Advance Directives; 62% of outpatients wanted to discuss the use of life sustaining treatments (ibid).

There is a large amount of literature on the development and use of advance directives in the community setting but little consensus on their benefits, as noted below. There are several practical issues that relate to the uncertainty of benefit. Patients do not always have the directive easily accessible, which may make it unavailable to clinicians at the time of a medical crisis or admission. Uncertainty about the need and the responsibility for ensuring the documents are updated and maintained is also controversial.

Advance Directives in the hospital setting

Older patients admitted to hospital have a higher risk of death during hospital stay than do younger patients. For this reason, autonomy and participation in decision-making are important for hospitalized seniors and to their families. Many have a desire for information about treatment and care options and involvement in end-of-life decision making about a variety of issues (Ross 2000). Most studies indicate that there is a need to strengthen both the quantity and quality of communication between health care providers and seniors and their families about end-of-life issues and need to heighten the awareness of seniors, families and health care providers about advance directives, including their possibilities and limitations (ibid).

Despite the increased publicity and awareness about end of life decision-making and advance directives, it is common for patients to not have orders related to end of life care preferences (e.g. No CPR, No intubation, etc.) on their chart. Studies have found that barriers preventing physicians from approaching patients to discuss end of life preferences include the perception that the patient is not sick enough, the possibility of the discussion upsetting the patient, the physician's discomfort with the process, lack of opportunity and a belief that it is the responsibility of the primary care physician.

Patients and families are familiar with the concept of **CPR** but have limited understanding of the procedure and generally overestimate its benefit. Most patients are interested in being involved in discussions about **CPR** and in sharing responsibility for decisions with physicians; however, older patients who participate in these discussions may have variable decision-making capacity. Physicians do not routinely discuss **CPR** with older patients, and patients do not initiate such discussions. When discussions do occur, the information provided to patients or families about resuscitation and its outcomes is not always consistent and does not always reflect the established expected outcomes. CPR and resuscitation options are medical decisions like any other treatment and as such a patient's preference may not be the treatment offered or provided.

A survey of critical care nurses indicated that 18% of hospitals where respondents were employed had a written policy on advance directives; 46% of respondents did not know if such a policy existed (Leith 1998). Other findings include:

- 18% of respondents routinely asked about advance directives on admission to hospital.
- 80% had cared for at least one patient who had an advance directive, indicating that the majority of critical care nurses surveyed had some experience with advance directives
- 88% responded that when they had cared for a patient with an advance directive, a copy was placed in the patient's chart.

- Consistent with other research findings, respondents indicated that advance directives are not always followed for a variety of reasons, including: physicians ignoring the patients' directive, families refusing to honor a patient's wishes and directives not being followed because they were hand-written.

Benefits of Advance Directives:

Benefits to executing directives include maintenance of personal autonomy, comfort for family members when making difficult decisions for their loved ones and avoiding court involvement in decision making. Having an appointed surrogate decision maker removes health professionals from the difficulty of appointing someone in a moment of crisis (Cramer 2001).

The vast majority of recent studies concur that, advance care planning which includes formal advance directives have a great deal of potential as a process and tool for facilitating communication among the patient, family and physicians (Norlander 2003; Hoffman 1997). Scenario based directives can provide useful information and provide maximum predictive power regarding a patients' wishes by allowing for sensible assumptions with respect to clinical situations. Communication between patient and designated surrogate decision maker is recommended in all relevant literature. Prior discussion is essential for clarification of intentions, wishes and values and may reduce guilt and stress of substitute decision makers when the time comes. It is also recommended that the patient review their document with physicians and family every year or two years. Although there is widespread recognition of the value of discussion and communication with decision makers about advance directives before a crisis or illness occurs, according to the literature, these discussions do not usually take place.

Limitations of Advance Directives:

Although there are significant benefits to directives, studies have shown that most people do not complete them. Reasons suggested for this include that they 1.) put this kind of decision making off, 2.) found difficulties in preparing the documents, or 3.) are satisfied with their present informal arrangements and cannot foresee a time when they may be decisionally incapacitated. Studies have shown that those most likely to complete an advance directive attach more importance to making their own medical decisions, have less trust in the medical system, have a higher level of education and/or have no living relatives. (Cramer 2001). Others have found that combining directive forms with interventions – e.g., education by health care providers, individualized information and counseling sessions and the use of videos and case scenarios – results in higher completion rates (Molloy 2000).

Current research has found little evidence that advance directives in themselves are effective in ensuring that a patient's wishes are honored (Norlander 2003). The primary shortcoming of advance directives relates to the predictive/speculative nature of the decisions the patient is making. Development of an advance directive is based on the assumption that the designated decision maker will act on a patient's behalf in a manner that he or she would approve of and that the person making the directive can accurately predict his or her actions in a situation of medical distress. Despite the focus on advance directives as a guarantor of patient autonomy, the usefulness of the directive presupposes that a person's future oriented preferences will remain constant over time. Recent studies have shown, however, that this is not always the case – people tend to change their views about treatment and care over the course of an illness (Koch 2001).

Furthermore, directives are not always adequate guides for surrogate decision makers. While they may provide general directives, they are most often insufficient to guide decisions more specific to complex medical situations. Family members may find it difficult to implement directives that may shorten a person's life and or require complex medical decisions (Koch 2001).

The success of advance directives is dependent on a number of assumptions (Koch 2001):

- 1.) Healthy people have sufficient knowledge and experience to make judgements about quality and satisfaction with life in the context of illness or disability; healthy people can accurately compare healthy and restricted states.
- 2.) A healthy person can accurately predict what he or she would want in extremes.
- 3.) Individual perceptions remain constant regardless of the physical or social context.
- 4.) The degree to which a person's physical condition deviates from the norm is of central importance.
- 5.) The patient is always the best judge of appropriate treatment at any moment.

Unless there is adequate communication between patients, health care workers and institutions, advance directives are unlikely to improve the decision making process (Molloy 2000).

According to the recent article "Is a living will the answer?" by Dr. Michael Gordon, a recent report for the Hastings institute shows that the benefits of living wills may be exaggerated and studies at the University of Michigan have shown that living wills rarely make a difference (Gordon 2005). (*Note: a 'Living Will', defined as "A document that states how we wish to be treated, if we become incapacitated by illness, injury, or old age", is functionally similar to an Advance Directive*). Writing a living will that can anticipate and provide instructions for every eventuality is virtually impossible (ibid). Surrogate decision makers appointed by a living will must understand the principles and values behind the instructions in a living will and must interpret them in light of the clinical situation. Therefore the most important aspect of a living will is the discussion that takes place with family members (ibid). While it is impossible to cover all potential situations in a living will, clear discussion with family about values and beliefs related to dying and end of life will help reach a common understanding of what to do when the situation arises (ibid; Singer 1998; Ho 2000; Ross 2000; Blondeau 1998 & 2000).

Care and cost implications:

The effect of advance directives on health care costs is a subject of debate (Singer 1996). The presence of expressed patient wishes about end of life care had a significant effect on nurses' selection of level of care. In the absence of an advance directive, 59% of the nurses chose the most intensive level of care; in the presence of an advance directive this figure was only 31% (Lavoie 1999). It is inferred from this finding that this may result in some health care savings. Further more, a randomized, Controlled trial (RCT) of the implementation of Dr. Molloy's 'Let Me Decide' Advance Directive with trained health professionals in nursing homes reported fewer hospital admissions and less use of health care resources. Thus, advance directives may lead to cost savings in health care (Molloy 2000; Rockwood 2001). Other studies have not replicated these findings. In particular while two RCT's of directives failed to show a reduction in costs, they recruited critically ill inpatients and young outpatients and their small sample sizes and accounting have been criticized (ibid).

Advance Directive tools/forms:

None of the articles in this search provided a critical review of any single Advance Directive tool/form and none of the articles compared the strengths and limitations of one form versus

another. This search focused on Ontario-based information and Canadian information as much as possible. It seems that the most predominant Advance Directives forms in Ontario are Dr. Molloy's "Let Me Decide", the University of Toronto's Joint Centre for Bioethics Living Will, developed by Peter A Singer, and the government of Ontario's recently developed "Guide to Advance Care Planning". In addition, as mentioned earlier, some Ontario hospitals and LTC facilities have policies regarding the use of Advance Directives, some have developed their own advance directive forms (Hoffman 1997). These have not been published.

Conclusions:

To foster the best care, advance care planning must evolve from a document-based system of healthcare directives focused on specific treatment choices to an ongoing dialogue with patients and family members about health care outcomes (Norlander 2003). Although embedded in the social process of advance planning, written advance directive forms may not be the central or defining feature of the process. This research suggests that written forms are not necessarily the desired output for advance care planning; many patients may be more satisfied with a discussion about their wishes with a family member. According to the findings of these recent research articles, the focus of advance planning should not be on the completion of a directive per se – but should be broadened to include the important role of communication with family members.

Furthermore, given patients' limited understanding of CPR and outcomes, and that some patients lack interest in discussing EOL treatment preferences, it is reasonable to conclude that for the situation to improve, physicians should be responsible for initiating these EOL conversations directly with their patients. In doing so, physicians should consider involving family members as the majority of patients and families view CPR decision making as a collaborative experience between the health care provider, the patient and the family. For EOL communication strategies to be successful, health professionals should attempt to engage the triad of the provider, the patient and the family member, when possible and when considered desirable by the patient (and their family). Documentation of discussions and patient preferences may help to minimize misunderstandings and increase the stability of the decision during subsequent admissions to hospital.

Recommendations:

It is clear from this review that there is a high value placed on the discussion involved in the advance directive process. From this, our recommendation is to encourage early, open and ongoing communication about a patient's wishes so that his/her values about end of life care are well known and understood by family members and healthcare professionals.

The literature review has not found any evidence for or against the use of a structured tool to help capture the expressed wishes of the patient. If due diligence is spent talking out one's health wishes in advance, a reliable way of capturing this information is recommended. The commonly used tools "Let Me Decide" by Dr. D.W Molloy, the University of Toronto's Joint Centre for Bioethics Living Will, developed by Peter A Singer, and/or the "Guide to Advance Care Planning" by the Ontario Seniors' Secretariat may be helpful in terms of framing these discussions and wishes for future reference.

Literature search strategy – please see next page

Advance Directives Literature Review – Search Strategy:

Database: Ageline, CINAHL, HAPI, Ovid MEDLINE(R), PsycINFO Search Strategy:

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- 1 Advance Directives.mp. [mp=ti, ab, de, id, hw, it, ac, ot, nm, sh, tc] (6723)
 - 2 Canada.mp. [mp=ti, ab, de, id, hw, it, ac, ot, nm, sh, tc] (93209)
 - 3 Ontario.mp. [mp=ti, ab, de, id, hw, it, ac, ot, nm, sh, tc] (20758)
 - 4 1 and 2 and 3 (20)
 - 5 1 and 3 (46)
 - 6 1 and 2 (180)
 - 7 2 or 3 (108001)
 - 8 1 and 7 (206)
 - 9 remove duplicates from 8 (172)
 - 10 limit 9 to abstracts [Limit not valid in: Ageline,HAPI; records were retained] (83)
 - 11 limit 10 to english [Limit not valid in: Ageline,HAPI; records were retained] (83)
 - 12 limit 11 to english language [Limit not valid in: Ageline,HAPI; records were retained] (83)
 - 13 limit 12 to human [Limit not valid in: Ageline,CINAHL,HAPI; records were retained] (79)
 - 14 limit 13 to humans [Limit not valid in: Ageline,CINAHL,HAPI,PsycINFO; records were retained] (79)
 - 15 limit 14 to yr="1985 - 2006" [Limit not valid in: HAPI; records were retained] (79)
 - 16 limit 15 to tests & measures [Limit not valid in: Ageline,CINAHL,HAPI,Ovid MEDLINE(R); records were retained] (76)
 - 17 limit 16 to all journals [Limit not valid in: Ageline,CINAHL,HAPI,Ovid MEDLINE(R); records were retained] (76)
 - 18 limit 17 to peer reviewed journal [Limit not valid in: Ageline,CINAHL,HAPI,Ovid MEDLINE(R); records were retained] (76)
 - 19 limit 18 to psycarticles journals [Limit not valid in: Ageline,CINAHL,HAPI,Ovid MEDLINE(R); records were retained] (76)
 - 20 limit 19 to yr="1990 - 2006" [Limit not valid in: HAPI; records were retained] (76)
 - 21 limit 20 to yr="1995 - 2006" [Limit not valid in: HAPI; records were retained] (49)

- 22 from 21 keep 1-10 (10)
23 from 21 keep 41-49 (9)

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