

The Allied Health Care Professional's Role in Assisting Medical Decision Making at the End of Life

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As a patient approaches the end of life, he or she faces a number of very difficult medical decisions. Allied health care professionals, including speech-language pathologists (SLPs) and occupational therapists (OTs), can be instrumental in assisting their patients to make advance care plans, although their traditional job descriptions do not include this role. The allied health care professional is often in a trusted position, permitting insight into the values and beliefs of the patient and facilitating the depth of communication necessary when making difficult decisions. Professionals who work with clients at the end of life need to be aware of the many issues surrounding end-of-life decision making and the preparation of advance directives for care. This article provides an overview of the complex issues the practicing clinician needs to keep in mind when assisting clients with advance care planning. This service requires that clinicians step outside their roles as rehabilitation experts, a move that is supported by professional associations. The concepts of medical decision making and informed consent are discussed in the context of decisions made in advance of illness at the end of life. The professional needs also to be aware of the legalities of advance decision making, as laws and statutes differ between states/provinces. There are overarching pieces of legislation that inform local legal and policy issues; the impact of these is briefly addressed. Various forms of documenting advance care plans, as well as their strengths and weaknesses, are discussed. Decision models are introduced as a means of guiding the clinician to provide quality care. Means of offering practical assistance to the client, such as motivational interviewing, the careful selection of appropriate educational material, and prevention of undue influence on the patient are discussed. Finally, the role of the allied health care professional in advocating for the client during the implementation is addressed. Understanding how the advance care plan should be implemented when a patient becomes incapable is essential when advocating for and protecting the rights of the patient. When a professional is prepared with the requisite understanding of all of the facets of advance care planning, he or she can become a strong ally for the patient and the family at this very important phase of life. **Key words:** *advance care planning, advance directive, allied health care professional, decision models, end of life, motivational interviewing, proxy, speech-language pathology*

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WITH THE PROGRESSION toward patient-centered care and away from more paternalistic models of medical treatment, patients are being asked more and more to make decisions regarding their health care. They may be offered choices of standard

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medical treatments and interventions, such as medications, occupational therapy, physical therapy, and speech-language pathology. In many cases, they may also be given a primary role in making decisions regarding aggressive treatments/interventions, for example, chemotherapy, radiation, and organ transplant. Patients may also face decisions regarding less familiar alternative or holistic treatments (e.g., acupuncture and naturopathy) or cutting-edge technology (e.g., gamma knife, stem cell treatments).

The difficulty people experience when facing medical decisions is often increased at the end of life when a highly charged emotional tone complicates personal situations and judgment, or cognition may be taxed to the limit because of the presenting medical conditions. An individual reaching the end of life may be faced with a dizzying array of options. Decisions regarding cessation of medication, cardiopulmonary resuscitation (CPR), and provision of life support may be requested or required by the health care provider. Patients may feel legitimately overwhelmed when making these decisions. Any member of the health care team, including allied health care professionals, in general, and speech-language pathologists (SLPs) specifically, may thus be called upon by the patient to act in the role of "medical expert" and assist in the decision-making process. This can be an unfamiliar and difficult role for the professional, especially if the person is not working in a geriatric or palliative care setting. The aim of this paper was to discuss the many facets of medical decision making at the end of life and to provide some guidelines that may assist the professional to provide the best person-centered care and support possible at this crucial juncture in the patient's life.

MEDICAL DECISION MAKING AT THE END OF LIFE

Increasingly, patients are asked to consider treatments well ahead of their implementation, especially when the patient has a life-threatening illness that is expected to remove

his or her ability to make decisions independently. Decisions for care that are expressed ahead of time can be documented in an advance directive (AD), also known as an advance care plan or living will. In this paper, the process of making an AD will be referred to as advance care planning. Depending on the jurisdiction, ADs may be accepted in written, oral, or other form. ADs are often advocated for people with chronic illness and at the end of life, as such documents can serve as a guide for the medical team and for the family when making decisions in the patient's stead.

The advance care decisions that a patient may be asked to make as are as varied as the conditions and personal circumstances they present. Although it is beyond the scope of this paper to present a comprehensive review of all possible treatments that might be covered by advance care plans, some of the most common options are presented in Table 1. Clinicians should have an evidence-based understanding of the risks and benefits of each of these treatments, as well as others that may be applicable to their domains of practice. This is the first step for a clinician to be able to provide assistance to the patient in decision making, as it is important that clinicians and patients have a common vocabulary when discussing treatment.

THE ROLE OF THE ALLIED HEALTH CARE PROFESSIONAL IN ADVANCE CARE PLANNING

Allied health care professionals are defined as health care providers with professional degrees, certification, and licensure, who are neither physicians nor nurses. This large group includes occupational therapists (OTs), physical therapists (PTs), and SLPs. Traditionally, such professionals have not been seen as important players in the decision-making process of their patients near the end of life. Although little has been written about the role of allied health care professionals in decision making for advance care planning,

Table 1. Treatments That May Be Addressed in Advance Care Plans

Treatment	Description	Risks
Resuscitation	A process administered to a person in cardiac arrest or fibrillation by which compressions are administered to the chest to affect heart massage, and ventilation is provided by a machine or another person, with the aim of restoring spontaneous heart rhythm and respiration.	May cause rib fractures, lung punctures, and overinflation of the lungs. Has a low rate of success for anticipated deaths and is most successful for sudden cardiac failure.
Ventilation	Process by which a person receives assistance in breathing by mask or by endotracheal tube (i.e., intubation).	The person is generally unable to speak or has great difficulty. Patients who are intubated often require sedation, restraint, or both to prevent self-extubation.
Nonoral feeding	The provision of nutrition by tube. Feeding tubes are most often placed through the nasal passage into the stomach (nasogastric) or through the abdominal wall directly into the stomach (gastrostomy) or upper portion of the small intestine (jejunostomy).	Risks include nausea, diarrhea, allergy to the liquid nutrition, irritation of the throat (nasogastric feeding), and infection of the stoma (gastrostomy and jejunostomy).
Artificial hydration	The provision of water through a nasogastric, gastrostomy, or jejunostomy tube, directly into a vein (intravenous hydration) or under the skin (hypodermoclysis).	If provided by tube, the risks are the same as those for tube feeding. Intravenous hydration has a risk of discomfort, collapsed veins, and infection. Hypodermoclysis carries a risk of infection and local discomfort.
Narcotic pain control	Narcotic pain relievers (e.g., codeine, morphine, hydromorphone, methadone) can be effective in reducing the perception of pain.	Risks include constipation, nausea, vomiting, confusion, loss of consciousness, and suppression of spontaneous respiration.
Dialysis	Performed as a palliative measure for kidney failure to remove waste and excess water from the body. In peritoneal dialysis, the abdominal cavity is filled with fluid that removes waste by osmosis and then is drained. Hemodialysis filters blood directly by a machine.	Side effects include nausea, weakness, low blood pressure, and sepsis. Either process is time consuming and limits the person's independence.
Modified diets	Given to people who have difficulty feeding themselves, chewing, and swallowing. Foods may be chopped or pureed and liquids may be thickened. Certain foods are restricted altogether.	People receiving modified diets often complain that their enjoyment of meals and social interaction are decreased as a result.

this area is receiving increased attention from researchers.

The role of the interdisciplinary team when supporting medical decisions has been supported by a large research consortium (Légaré et al., 2011). Many professional associations representing allied health care professions are now stepping forward to offer guidelines to clinicians working in end-of-life care settings. In particular, the American Speech-Language-Hearing Association (2012), the American Occupational Therapy Association (2012), and the Canadian Association of Occupational Therapists (2012) offer extensive resources for SLPs and OTs on their Web sites.

Involvement in end-of-life decision making requires allied health care professionals to understand decisions that need to be made by the patient from personal, medical, and holistic viewpoints. In addition, these discussions and decisions may be very uncomfortable for the clinician if he or she is not habituated to stepping outside of the pure rehabilitation paradigm and looking at the situation from the point of view that the patient will not recover and may not wish medical intervention. Professional practice guidelines for end-of-life care, available from one's licensing body or professional association, can help clinicians more comfortably navigate this paradigm shift. Given that allied health care professionals are not necessarily experts in all facets of medical treatment, questions could be raised about why they should assist with advance care planning. Although the physician or nurse may seem like a more logical choice for this role, the involvement of allied health care professionals offers some appealing advantages.

Anecdotal evidence indicates that allied health care professionals may know their patients better than physicians, especially with regard to the fabric of their lives, their beliefs and values, and their expectations and aspirations. OTs, PTs and SLPs spend much more time with their patients than physicians do. An appointment with an allied health care professional often lasts from 30 to 60 min in rehabilitation or outpatient service, whereas visits

with a physician are often limited to approximately 20 min (Chen, Farwell, & Jha, 2009). This gives patients time to think of and ask questions outside of their immediate medical concerns, which the shorter medical appointment may not permit.

Technical competence, empathy, and caring have been shown to result in trust of rehabilitation professionals (Manderson & Warren, 2010). Research with physicians shows that trust is associated with greater involvement in care, length of relationship, frequency of visits, and lack of disputes (Hall et al., 2002; Shenolikar, Balkrishnan, & Hall, 2004; Trachtenberg, Dugan, & Hall, 2005). The nature of the services offered by an allied health care professional may be more intimate than those provided by a physician, associated with care often being provided frequently and on an individualized basis, centered on activities related to engagement in daily living such as bodily functions, self-care, and communication. This may result in an open relationship, which then lends itself to the discussion of the patient's thoughts and emotions. Allied health care professionals may be involved with advocating for other aspects of patients' care as well, especially if they are adopting the role of case manager for the multi- or interdisciplinary team (Carr, 2005; Dufresne, 1991; McCullough, 2009). It would thus not come as a surprise that patients trust them. Thus, the allied health care professional is a likely target for the patient's question: "What do you think I should do?" The allied health care professional can be well positioned to offer the needed and desired assistance at this crucial time.

Allied health care professionals are unlikely to assist with decisions regarding specific medications or surgical approaches. However, decisions that have direct relevance to the allied health domain may be important to the client. Questions and concerns regarding oral or alternate nutrition and hydration, the impairment and subsequent facilitation of communication as a result of illness, the placement of a tracheostomy, or the use of ventilation equipment are most likely

to be addressed to the SLP. Nevertheless, professionals should keep in mind that because of their role as a trusted professional, questions not specific to their profession may also arise.

FORMULATION AND COMMUNICATION OF WISHES BY THE PATIENT

In practice, many patients do not have an AD despite the enthusiastic support for them by the medical profession. It has been suggested that, although older individuals may have plans for their demise (e.g., wills and funeral arrangements), they tend not to have explicit plans for serious medical illness (Carrese, Mullaney, Faden, & Finucane, 2002). Recent data from the U.S. Department of Health and Human Services (2010) indicate that in the United States, only 41% of White individuals and approximately 12% of Black and Hispanic individuals older than 65 years who are receiving home health care have an AD. The proportion of individuals having an AD is higher in nursing homes (75%, 41%, and 50% for White, Black, and Hispanic, respectively), but the cultural differences remain. These statistics confirm studies that show culture to be an important determinant in an individual's willingness to engage in advance care planning (Wittenberg-Lyles, Villagran, & Hajek, 2008).

Communication of wishes for care to medical professionals and family can be problematic. Clements (2009) demonstrated that even among people with an AD, 60% did not communicate the contents to their family and only 16% had communicated their wishes to their physician. Another cross-sectional study of a group of community-living older adults showed that, whereas 51% had an AD, 41% had not expressed their wishes to family regarding life-sustaining treatment and 53% had not discussed their thoughts about quantity versus quality of life with family members (Fried et al., 2010). Ninety percent and 95% of the sample participants, respectively, had not discussed these issues with their physicians (Fried et al., 2010). However, informing others of the contents of an AD is by definition

necessary to its implementation, which suggests that many people who have ADs may not have them implemented correctly.

Some patients feel that not completing a written AD, but simply discussing their wishes with a family member, is sufficient. Highly publicized court cases (e.g., *Schaiwo v. Schaiwo*, 2005) have highlighted the conflicts that can arise when there is disagreement regarding the content or veracity of what a person's verbally expressed wishes were. Some health care facilities attempt to manage this difficulty by mandating the formulation of written advance directions by patients as a condition of admission (Lambert, 2007). However, forcing an individual to make decisions for care is considered unethical and is illegal in some jurisdictions, and facilities are leaving themselves open to complaint or lawsuit if any patient or family decided to complain (Lambert, 2007). Evidently, a change in institutional and public policy is needed if it is desired that all patients engage in advance care planning in an ethical manner, that is, if they willingly contemplate their beliefs and then voluntarily make and communicate the contents of their ADs (Etchells, Sharpe, Dykeman, Meslin, & Singer, 1996). Admittedly, few clinicians have the legal expertise, interest, or time to participate in the legal or policy reform process on an individual basis. However, through awareness of the legal/ethical pitfalls and advocating for the rights of the individual patient within the facility, an individual clinician may begin to influence policy within the facility.

LEGAL ASPECTS OF ADVANCE DECISION MAKING

Before any medical procedure is performed on a patient, professionals must ensure that patients or their legal representatives give what is termed *informed consent*. According to the American Medical Association (2011), informed medical consent is obtained when the practitioner explains the diagnosis; the nature, purpose, risks, and benefits of the treatment; the nature, purpose,

risks, and benefits of any alternative treatments; the consequences of not having treatment; and the answers to any questions the patient has regarding this information to the patient's satisfaction. The patient (or representative) then considers and decides whether or not to give consent for treatment.

All treatments, from the most benign to the most aggressive, have potential benefits and drawbacks. It is the weighing and balancing of these against the patient's beliefs and values that must be accomplished to come to a decision about care (Lambert et al., 2005). Patients may decide to forego a treatment, accept the treatment for a specified period of time to assess its success, or unconditionally agree to treatment (Shaw, 2010).

In both Canada and the United States, federal law sets the stage for the provinces and states, respectively, to operationalize definitions of medical decision making and the assignment of proxy decision makers. It is guaranteed in provincial/state law in Canada (Dunbrack, 2006; Lambert et al., 2005) and the United States (Stein & Kerwin, 2010) that the patient has the ultimate decision for self-determination for health care and must give informed consent for any treatment. If the individual is not capable of making his or her own decisions, legal mechanisms are in place in many jurisdictions to assign an appropriate proxy decision maker, whose responsibility is to ensure that the patient's wishes and beliefs are respected (Castillo et al., 2011; Dunbrack, 2006; Sabatino, 2007).

A sample of these laws is presented in Table 2. This table is not exhaustive, and the individual practitioner should be aware of the laws applicable in his or her area along with any updates or changes that are made with time. When no laws regarding ADs or assignment of proxy decision makers are in place within a jurisdiction, medical facilities nevertheless apply these concepts as an ethical requirement for quality care (Nelson et al., 2010). Therefore, regardless of the legal standing of ADs within a clinician's jurisdiction, he or she should be aware of the legal issues involved in advance care planning.

The legal barriers and ethical pitfalls of making decisions for future care have been debated at length by medical professionals, lawyers, policy analysts, and ethicists (e.g., Castillo et al., 2011; Dresser, 2003; Minkoff & Marshall, 2009). Advance directives attempt to guarantee that patients receive the level care they wish to receive, without the application of nonbeneficial treatments (Yuen, Reid, & Fetters, 2011). Medical professionals provide treatment in ways that they know are desired by the patient and consistent with the care plans of facilities for the use of human and material resources (Lambert, 2005). However, the informed consent process is known to be flawed.

Professionals may expect more common medical treatments and some aggressive treatments to be at least somewhat familiar to many people because of their place in popular culture and therefore may not give complete information regarding a treatment to a patient. However, many studies have shown that health literacy is poor even for basic treatment options (Baker et al., 2007). This is especially true among people who are elderly and those with chronic physical and mental health conditions (Moore, 2010)—the very people who need to make decisions for care. It has been demonstrated that older adults have little accurate knowledge about CPR (Frank et al., 2003; Godkin & Toth, 1994), have fixed preconceived notions about who should receive CPR, and overestimate the effectiveness of resuscitation by 300% (Miller, Jahngen, Gorbein, & Simbartl, 1992). If even the most basic and familiar treatment is not thoroughly and exhaustively explained, informed consent cannot be assumed to have been given.

In addition to failing to offer complete information to the patient, clinicians may also extrapolate (inappropriately) from a request not to be resuscitated that the request extends to withholding of other treatments (Yuen et al., 2011). Institutional and population interests are also known to subjugate the patient's interests (Karlawish, Fox, & Pearlman, 2002). One of the strongest arguments against

Table 2. Sample Legislation on Advance Care Planning in the United States and Canada

Region	Law	Purpose
United States Federal Law	Uniform Health Care Decisions Act (1993) ^a	Recognizes right to accept or decline medical treatment, and any form of AD. Wording to allow withdrawal of death-delaying procedures not adopted in all states. Provides a model for default surrogate law.
	Patient Self-Determination Act (1990)	Requires many hospitals, nursing homes, home health agencies, hospice providers, HMOs, and other health care facilities to provide information about ADs on admission. Ensures the right of the patient to make decisions regarding his or her own health care, to accept or refuse medical treatment, and to make an AD. Admission or treatment based on the presence or absence of an AD is prohibited.
	Patient Protection and Affordable Care Act (2009) ^b	Medical treatment can be refused on the basis of religious reasons (First Amendment Rights), right to privacy (due process issues of 14th Amendment), and liberty interest (14th Amendment).
Cases	Quinlan (1976)	Supreme Court found that the right to remove ventilator and right to privacy were constitutionally guaranteed.
	<i>Cruzan v. Dir., MO Department of Health</i> (1990)	Solidified constitutional right to refuse life-sustaining treatment based on “clear and convincing” evidence of dying person’s wish to have life support removed, given at a time that he or she was competent. Recognized right of proxy to act on behalf of an incapacitated person.
	<i>Schaivo v. Schaivo</i> (2005)	Reaffirmed Cruzan.
State statutes	Summarized in Castillo et al. (2011)	Verifies locally applicable legislation.
Canada Federal Law	Charter of Human Rights and Freedoms	Guarantees right to autonomous decisions and freedom of spiritual belief
Provincial law	Summarized in Dunbrack (2006)	Verifies locally applicable legislation.

Note. AD = advance directive; HMO = health maintenance organization.

^aFrom *Uniform Health-Care Decisions Act (USA)*, Uniform Law Commission, 1993. Retrieved June 14, 2011, from <http://www.upenn.edu/bll/archives/ulc/fnact99/1990s/uhcda93.pdf>

^bFrom “Patient Protection and Affordable Care Act of 2009, U.S. House of Representatives, 2009, H.R. 3590, 111th Cong., 1st sess., § 1233 (2009).

the AD is that it is impossible for an individual to receive all of the necessary information on all of the possible treatment options and consequences to give informed consent (e.g., Shaw, 2010). Arguments are made that instead of listing individual medical decisions regarding specific treatments, the AD should explain the values and beliefs that would inform a decision at the time of a medical crisis or intervention choice, thereby allowing the proxy decision maker to make an educated decision from the point of view of the patient (e.g., Rosenfeld, Wenger, & Kagawa-Singer, 2000; Sudore & Fried, 2010).

In an attempt to streamline advance care planning and ensure that the directives are easily understood, many facilities use a standardized checklist of treatment options in lieu of an individually written AD. Generic examples (from Lambert, 2007), which are not recommended, appear in Appendix 1. These forms tend to be reductionist in nature and do not address values and beliefs (Lambert, 2007; Vogel, 2011). The Canadian Hospice and Palliative Care Association is moving to improve the process of planning for the end of life by discouraging the use of these checklists and by promoting conversations regarding goals for care and values regarding care (Vogel, 2011). Calls have gone out for the United States to adopt a similar approach (Castillo et al., 2011). Such a radical change of approach would ultimately require the modification of laws on advance care planning. This paradigm shift was first initiated as the Uniform Health Care Decisions Act by the American Bar Association in 1994 but has been adopted thus far only by a few states (Castillo et al., 2011; Uniform Law Commission, 1993).

Despite flaws in the system, there is a longstanding and strong clinical support for encouraging patients nearing the end of life to make medical decisions in advance, and ADs are unlikely to disappear or change in the near future (Gillick, 1995; Kelner, Bourgeault, Hebert, & Dunn, 1993; Lambert et al., 2005). Thus, clinicians working with patients at the end of life need to be ready to assist pa-

tients and their proxy decision makers in the decision-making process to allow the best informed decision about care that is possible.

HOW PATIENTS MAKE DECISIONS

An awareness of how patients make these important decisions, and how they are ultimately implemented, is required. Several theoretical models of how patients make medical decisions (Noone, 2002) and ADs (Bisson, Hampton, Rosser, & Holm, 2009; Hajizadeh, Crothers, & Braithwaite, 2010; Heyland, Tramer, & Feldman-Stewart, 2000) have been proposed, which may be of interest to the clinician assisting in advance care planning. These models attempt to explain the types of information that are weighed by the patient. It is beyond the scope of the paper to discuss each in detail, as they are diverse, but for clinicians interested in "how clients think," they make interesting reading.

In a qualitative study, Lambert et al. (2005) interviewed a population of older adults in long-term care reaching the end of life regarding the influences for their decision making. In this population, much more value was assigned by patients to their own experiences, values, beliefs, and preconceived notions than to objective information regarding their medical conditions or treatment (Lambert et al., 2005). This finding underlines the necessity of an individual counseling approach in addition to the provision of educational material. In particular, participants' past experiences with the death of a loved one, or with serious illness of oneself or a loved one, were extremely influential to an individual's care decisions. An important consideration for many patients was a perceived need for a loved one to provide care during illness or treatment. This necessity contributed to the feeling of being a "burden" and made patients less likely to accept life-prolonging treatments (Lambert et al., 2005). In addition, negative experiences of suffering or pain were strong factors in decisions against aggressive care (Lambert et al., 2005).

FACILITATING ADVANCE CARE PLANNING

Personal factors, such as values and spiritual beliefs, concern for oneself, concern for a caregiver, life experiences, educational level, and expectations about the impact of the AD, affect how a patient makes a decision for care. Such factors may also influence whether or not patients are willing engage in formal advance care planning at all (Alano et al., 2010; Levi, Dellasega, Whitehead, & Green, 2010). These factors are outside of the scope of influence of the medical professions; however, the likelihood of an individual completing an AD is also related to two important factors within the clinician's reach: (1) a personal approach by a health care professional, and (2) exposure to public campaigns and educational material to promote advance care planning (Alano et al., 2010). A number of practical suggestions for assisting a patient with advance care planning are summarized in Table 3.

Professional interactions surrounding advance care planning

Many factors intrinsic to the individual are weighed in making a decision for end-of-life care, and many patients will need guidance in sorting through the information available to them. Open, tailored discussions in a supportive environment can help individuals and care teams become aware of patients' beliefs and values, which may then help professionals support the decision-making process, making patients feel more comfortable about the advance care planning process (Fried et al., 2009). Allied health care professionals may also be instrumental in helping patients resolve internal conflicts and assisting them to arrive at satisfactory decisions (Lambert, 2005).

Motivational interviewing

Advance care planning has been conceptualized as a process of health behavior change (Fried et al., 2009), namely, thinking about and making a decision when this behavior

was not engaged in previously. Motivational interviewing is an interaction strategy that was introduced in the 1980s and has been gaining in popularity, especially in the past decade (Lundahl & Burke, 2009; Miller & Rollnick, 2002). The technique is used to help people explore their intrinsic motivation for certain behavior in order to bring about a voluntary change (Harvard Mental Health Letter Editorial Board, 2011; Lundahl & Burke, 2009). Hence, it is a good fit for advance care planning. Motivational interviewing has been shown to be effective in helping patients to adopt healthy behaviors in diverse areas of medical practice including kidney disease management (Martino, 2011), stroke (Byers, Lamanna, & Rosenberg, 2010), acquired brain injury (Medley & Powell, 2010), HIV infection and lifestyle, diabetes, diet and exercise, alcohol abuse, preventive oral care (Magill et al., 2010; Martins & McNeil, 2009; Williams & Bray, 2009), and engagement in treatment (Lundahl & Burke, 2009; Williams & Bray, 2009). Motivational interviewing acknowledges that simply providing education about a topic is not sufficient; rather, it is based on the view that individuals need to be aware of dissonances between their actions and their values and beliefs in order to change behavior (Harvard Mental Health Letter Editorial Board, 2011; Lundahl & Burke, 2009). Although no research has been done in this area to date, advance care planning depends on a balance of knowledge and personal beliefs and values; thus, motivational interviewing holds promise for assisting patients to come to a decision for advance care planning.

Research has suggested that motivational interviewing can be applied in the presence of a significant other without affecting the effectiveness of the intervention (Magill et al., 2010). Although Magill et al. (2010) recommended that further study of the effect of the significant other on the interaction is needed, this technique shows promise in improving patient engagement in advance care planning, including when loved ones wish to be present during the process. Research also has shown that severity of disease, as well as patient

Table 3. Suggestions for the Speech-Language Pathologist or Other Allied Health Care Professional Providing Assistance for Advance Care Planning

Time frame	Suggestions
Before meeting with the client	<p>Be aware of the laws and policies in your jurisdiction and facility.</p> <p>Review profession-specific practice guidelines.</p> <p>Review the client's medical record to be sure you are aware of other discussions or decisions that have occurred.</p> <p>Research an appropriate theoretical model for decision making if you feel more comfortable having a guideline for the conversation to be sure you cover all eventualities.</p> <p>Find educational materials appropriate to the client's health literacy, age, and functional/cognitive status.</p> <p>When possible, have a variety of possible materials available so that more than one can be offered.</p>
When meeting the client	<p>Be open to the client's wish to discuss advance care planning at the present time (or not). Be receptive to rescheduling.</p> <p>Be empathetic to the difficulties many experience in making difficult medical decisions in advance.</p> <p>Keep in mind that there is no right and wrong answer to care decisions so long as the decision is in line with the values and beliefs of the client.</p> <p>Ask clients why they feel the way they do about a certain topic (e.g., "Why are you opposed to tube feeding?"). Indirect probes (e.g., asking "Have you ever dealt with someone who was tube fed before?") may be more productive than a direct question (e.g., "Why do you feel that way?").</p> <p>Gently offer alternative reasoning (e.g., "Some people feel that . . .").</p> <p>Point out the discrepancies between their behavior and their beliefs (e.g., not making an advance directive when they do not wish certain interventions, or making a decision that is against their beliefs).</p> <p>Do not confront regarding any discrepancies. Present both sides of the argument and tactfully engage clients in expressing their reasoning.</p> <p>Ask if they are willing to make a decision, and if not, ask what other information or assistance they need.</p>
After meeting the client	<p>Follow-up with any requests for additional information or meetings.</p> <p>Carefully chart the verbal and emotional content of the meeting even if it outside your usual scope of practice.</p> <p>Outline any further discussions or consultations that need to take place with the client or proxy.</p> <p>Communicate the results of the meeting to the rest of the team.</p> <p>Continue to follow-up with the client to ensure stability of the decision.</p> <p>Advocate for the client's decision with other professionals and family members as necessary.</p>

gender and age, do not influence the effectiveness of motivational interviewing (Lundahl & Burke, 2009). This further supports its use for end-of-life decision making, as both men and women are faced with these decisions, the patient's health problems are likely to be severe, and the patients tend to be in the late adult or geriatric category. Motivational interviewing is increased in effectiveness with the addition of print communication (van Keulen et al., 2010), which supports the demonstrated efficacy of print material in educating patients and families about end-of-life decisions (Tamayo-Velásquez et al., 2010). The technique has been found to be effective regardless of the professional's original discipline, and a 2-day training seminar has been found to be an effective means of learning the technique (Lundahl & Burke, 2009).

Four key components make up a motivational interview (Miller & Rollnick, 2002). In the first step, the interviewer *expresses empathy* with the patient's situation and uses active listening techniques to fully understand the situation from the patient's point of view. The clinician then draws attention to or *develops the discrepancies* between the current behavior (e.g., difficulty in making an AD) and the patient's values and beliefs (e.g., not wanting to receive gastrostomy feeding or intravenous hydration). This is the stage in which the patient's values and beliefs are brought to the fore (e.g., a patient may believe that writing a directive will make the family angry or hurt). In the next step, *rolling with resistance*, the clinician avoids confronting any resistance to change, using techniques such as playing devil's advocate and presenting both sides of the argument (e.g., "How would the patient feel if the family were to be approving a treatment that the patient would resent having?" "What if a non-family member becomes the proxy decision maker?"). This step encourages patients in a nonconfrontational way to acknowledge and consciously process their values and beliefs, which tends to bring them to discuss the possibility of and express a commitment to change, which in this case means indicating

willingness to engage actively in advance care planning. Finally, in *promoting self-efficacy*, clinicians might ask clients how committed they are to engage in the new behavior (i.e., advance care planning) and ask what would need to happen to increase that level of commitment (e.g., the client would like to receive an information booklet about the legalities of making a directive and choosing a proxy). By allowing those needs to be identified and met (e.g., the SLP provides the requested information), this again increases the likelihood that the new behavior will occur (i.e., the client now has the information needed to make an AD; Harvard Mental Health Letter Editorial Board, 2011; Miller & Rollnick, 2002; Williams & Bray, 2009).

Decision models

Clinicians may find it useful to have a framework when approaching such a complex interview. Decision models have been advocated for end-of-life care planning that may be useful in assisting clinicians without formal training to assist patients. A decision model allows the patient and the clinician to follow a flowchart or similar visual aid, which guides them through a reasoning process in a concrete manner. A number of models are available; the choice of a model is heavily predicated on the clinical setting and the medical problems being presented. For example, a decision model for the development of an AD has been developed for chronic obstructive pulmonary disease (Hajizadeh et al., 2010). However, the outcome of such a model is a decision for or against specific treatment decisions; it does not elucidate the values and beliefs that underpin the decision. Other models of decision making (Bisson et al., 2009; Heyland et al., 2000; Lambert et al., 2005) may help guide a clinician to cover salient areas that may influence final care decisions. Molloy (2005) published a book and video series titled "Let Me Decide," which guides individuals through the formulation of an AD for care and the designation of a proxy for medical decisions.

Concerns have also been raised about these approaches. They can be criticized as not providing sufficient information regarding an individual's motivations and beliefs and for not presenting a sufficiently complex explanation of the medical decisions. Checklists for care used in many health care facilities (as illustrated in the Appendix) may also be used as interview guides by professionals, but they have similar weaknesses, as discussed previously (Lambert, 2007).

Educational material on advance care planning

Studies indicate that patients verify the health information obtained from professionals with supplemental sources such as newspaper, radio, television, and, in ever-increasing numbers, the Internet (Cutilli, 2010). Lambert et al. (2005), in a small sample of older adults, found that media played a minor role in decisions about ADs; however, this may change as the younger generation—which is more accustomed to television and the Internet—gets older. The allied health care professional has a role both in assisting patients to find appropriate health information and in interpreting it, as necessary.

Print material

A large quantity of educational material is available to educate patients on advance care planning. Many individuals now turn to the Internet for information, but the volume of information can be overwhelming. A Google search for “living wills information” yields approximately 298,000,000 results. Adding a location does not reduce the number of sites to a workable number; adding the search term “New York” gives more than 291,000,000 sites, and adding “Ontario” yields 22,000,000. A study of fourth-year occupational therapy students indicated that they did not feel sufficiently able to critically appraise the validity of Internet-based information (Brown & Dickson, 2010). Given the low level of health literacy in the general population, few people are in a position to read and critically appraise the information they are receiving.

Therefore, the likelihood of a layperson being able to find a high-quality Web site to inform them of the advance care planning process is fairly low. A recent review of Internet-based educational material on end-of-life decision making on palliative care Web sites revealed that a high level of reading skill is required and poor user-friendliness is common (Ache & Wallace, 2009). It is uncertain whether the patient would be able to use the information even if able to find it.

Many books are available on advance care planning. A search of AD books on a popular online bookseller yielded 321 ISBN numbers, with 60 of these having publication dates in 2000 or later. As many of these books would be available only through special order or via an online bookseller, a patient might not be able to appraise the applicability of the book to his or her particular situation, or its usability, before ordering.

Video information

Video information is also available. Six videotapes or DVDs were found at a major online bookseller, some of which had multiple versions targeted to different audiences (professional, family, and patient). A patient could also seek out a free resource, such as might be found on YouTube. A search of the keywords “advance directive” yielded 911 results (search results available at: http://www.youtube.com/results?search_query=advance+directive&suggested_categories=27%2C22). Of the top-25 search results sorted by relevance, all but one appeared to be from reliable sources such as universities, medical centers, physicians, or legal regulatory bodies (as, for example, opposed to laypersons or personal injury lawyers seeking clients, which may not provide valid or unbiased information). Patients would need to add search terms to narrow the results to meet their needs in terms of jurisdiction and level of complexity. For example, including client's primary diagnosis (e.g. chronic obstructive pulmonary disease, cancer, dementia) and the state or province where they reside could

give information more specifically tailored to the client's needs.

Combining methods

Results of studies assessing the relative success of verbal, video, and written methods of educating patients regarding advance care planning are inconsistent, although it seems that using multiple methods may be more effective than using a verbal approach alone (Durbin, Fish, Bachman, & Smith, 2010). It also has been found that passive information sources, such as video or leaflets, increase in effectiveness when paired with direct interaction with a professional (Tamayo-Velásquez et al., 2010). These results suggest that an individualized approach using multiple media presented over several sessions by a professional with knowledge of advance care planning may be best (Tamayo-Velásquez et al., 2010).

Common pitfalls in advance care planning

As clinicians become involved with patients, making care decisions and formulating ADs, they must be alert for factors that may compromise the integrity of advance care planning. Many efforts to promote end-of-life decision making are focused on individuals living in the community or previously "well" individuals who have suddenly become ill or infirm. Individuals with chronic physical and intellectual disabilities largely have been overlooked in policy making and implementation of advance care planning initiatives (Stein & Kerwin, 2010). Rehabilitation professionals are well placed to identify these individuals and to advocate for their rights to self-determination for health care.

The complexity and individual nature of the advance care planning process, and the necessary involvement of family members, bring the risk of a patient making a decision for care under the undue influence of another person. Several "red flags" for undue influence have been identified. These include social or environmental factors such as dependency, isolation, family conflict, and bereave-

ment; psychological and physical factors such as physical disability and making a will "on the deathbed"; mental disorders such as delirium, dementia, mood, and paranoid disorders; and legal factors, such as the instigation of a will by a beneficiary and the will not keeping with known wishes of the patient (Pesiah et al., 2009). Clinicians need to be alert for any of these potential signs and risk factors of undue influence. Undue influence may occur for many reasons. One qualitative study I conducted (whose data were never published) revealed many examples of this, including subversion of a care plan because of differing spiritual beliefs of the patient and the proxy and making an AD a requirement for admission to or prevention of expulsion from a care facility (Lambert, 2007). Advance directives made under circumstances such as these are suspect and cannot be considered to meet the requirement of informed, voluntary consent. Such unethical practices should be addressed through appropriate reporting and due process procedures.

In cases where undue influence is suspected, clinicians should explore the reasoning behind the decision with the patient. Perhaps, there was a factor previously unknown to the clinician or a change in the patient's personal situation that influenced a decision for or against a treatment and the decision is voluntary and well considered. Family involvement, which could be perceived as excessively influential by clinicians, might be entirely acceptable to and desired by the patient (Ho, 2008). However, because of the complexity of the process, it is possible that the patient misunderstands the benefit, risks, or possible outcome of a treatment or that there has been influence (intentional or not, malicious or not) by another person. In the case of undue influence, it is essential to help patients to explore "what *they* want," as opposed to what another person perceives as the best treatments for them. This can be accomplished through motivational interviewing and other counseling techniques. In cases where undue influence has been identified, the rest of the care team and possibly the ethics committee

of the facility may need to become involved to come to a resolution for the benefit of the patient.

ASSISTING IN THE IMPLEMENTATION OF AN ADVANCE DIRECTIVE

In the end of life, advance care planning is intended to assist the proxy decision maker—rather than the medical professional—in making decisions at the time that a medical intervention is being considered. As previously discussed, the proxy decision maker is chosen by the patient at a time when he or she is capable of making decisions. Alternatively, the proxy decision maker may be assigned according to legal procedures determined by local laws. The proxy would then be informed of any ADs or other wishes for care, which ideally would include what states of health or interventions would be acceptable for the patient. When a patient is temporarily or permanently incapable of making a decision regarding his or her care, the proxy is called upon to make the decision. If no proxy has been determined, some jurisdictions have a mechanism for assigning an alternate from within the patient's family and friends or from the legal system in the form of a legal guardian (Lambert, 2005; Swetz, Kuczewski, & Mueller, 2011). The proxy is legally and morally bound to follow the patient's AD or to make decisions that would follow the patient's unexpressed wishes with what is called "substituted judgment" (i.e., what the patient most likely would have decided for himself or herself; Stein & Kerwin, 2010; Sulmasy & Snyder, 2010). Making medical decisions based on the "best interests" or "therapeutic interests" of the patient is advocated in the absence of sufficient information to make a decision based on substituted judgment (Kapp, 2010). This standard is met by weighing the potential burden of the treatment with the expected benefit and knowledge of the patient's general values and beliefs whenever possible (Weissman, Quill, & Arnold, 2010).

Research has documented that spouses do not correctly report a patient's preferences

13% of the time in end-of-life scenarios and 26% of the time in scenarios regarding pain management. The accuracy of spouses is the highest among family proxies; it is lowest among adult children (Parks et al., 2011). Families in conflict also demonstrate lower accuracy in reporting the loved one's wishes (Parks et al., 2011). When a proxy's beliefs are not in concordance with those of the patient, the proxy may make decisions that are more concordant with his or her own beliefs or interests than with the patient's (Moorman, Hauser, & Carr, 2009).

The allied health care professional can assist the family in making decisions by using the principles of motivational interviewing or counseling to assist proxies to reflect on what the patients expressed as wishes for care; what they would say if they were able to fully comprehend their situation; and their beliefs, values, and experiences. A useful framework for guiding this conversation is available (Sulmasy & Snyder, 2010). Further measures for assisting a proxy decision maker to determine a care plan that is truly in the patient's best interests include making sure there is a common understanding between the proxy and the care team of the risks and benefits of the treatment, framing the decisions to be made around treatment goals, respecting emotions, active listening, and referral of the proxy to outside resources such as support groups or counseling (Weissman et al., 2010).

CONCLUSION

The issues surrounding care planning for the end of life are complex and can add considerable stress to a time that is difficult for patients and their families. Many allied health care professionals are in trusting relationships with their patients and thus are well placed to understand many of the issues that may influence a patient's decision-making process. They also possess the training, skills, and resources to assist in the process and to advocate for the patient within the medical team. Awareness of the legalities and ethical

issues surrounding advance care planning, the decision-making process for patients, the implementation of an AD, and some of the major difficulties that patients may experience

during the process can assist the allied health care professional to assist the client and their proxy in making the best health care decisions possible.

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Appendix 1 Example of Generic Advance Directive Forms

Forms used by facilities for ADs often follow one of the following types. These are forms not from actual facilities but are a gestalt of many forms reviewed by the author and are representative of the types of decisions that are requested. The length of the text is representative of what is often found on the forms. This type of form is not recommended by the author.

THE TREATMENT CHECKLIST

I (name) wish to receive the following treatments (check desired treatments):

1. CPR
2. Ventilation
3. Tube feeding
4. IV hydration
5. IV antibiotics
6. Transfer to hospital for assessment
7. Surgery
8. Other: _____

THE CARE PLAN¹

I (name) wish to receive the following care (choose one of the following four):

Level 1: Palliative care only. No assessment or treatment outside the facility. No CPR.

Level 2: No transfer to hospital, no CPR. IV hydration and antibiotics accepted. No tube feeding or ventilation.

Level 3: Transfer to hospital for reversible conditions. Tube feeding, IV hydration, and antibiotics accepted.

Level 4: All possible care including transfer to hospital, tube feeding, surgical intervention, ICU care, CPR, and ventilation.

¹Note that the "Levels" are not standardized, and what is a Level 1 in one facility will be assigned a different designation in the other.