

Advance Directives for End-of-Life Care and the Role of Health Education Specialists: Applying the Theory of Reasoned Action

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Submitted: April 22, 2011; Revised and Accepted May 6, 2011

Abstract

Quality end-of-life care is subjective and based on individual values and beliefs. An advance directive provides a legal means of communicating these values and beliefs, as well as preferences in regards to end-of-life care when an individual is no longer able to make his or her desires known. In many nations, advance directives are underused leaving many vulnerable to end-of-life care that may be incompatible with their personal preferences. Health education specialists can have a positive impact on this issue. Through programs provided in the community, individuals and particularly older adults, can be educated about advance directives and the role they play in ensuring personal wishes are carried out relative to end-of-life care. Application of the Theory of Reasoned Action provides a means of meeting the educational needs of older adults in regards to advance directives.

Key words: *Advance Directives, Health Education Specialists, Theory of Reasoned Action*

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The need to address end-of-life issues has been recognized internationally. A 2005 meeting of the International Work Group in Death, Dying and Bereavement with experts from Australia, Canada, Germany, Japan, the Netherlands, Norway, the United States and the United Kingdom proposed that end-of-life care ought to “be considered a public health priority”.^{1(p384)} This recommendation was based on many international changes such as an increase in the older adult population, gaps between the rich and poor in many nations, and changes in health care including the ability to extend life.

Recommendations from the meeting also included that all persons, not just professionals involved with the dying, be educated to be culturally, spiritually, socially, and emotionally sensitive to the needs of the dying and bereaved.¹ In order to be sensitive to the needs of the dying it is critical to understand their end-of-life wishes. Advance directives provide this understanding by guiding care decisions that are consistent with the values and beliefs of the dying. Yet, many individuals world-wide die without an advance directive in place.^{2,3} In some countries, dying without an advance directive is related to a lack of legislation legalizing an advance directive⁴ and in others, dying without an advance directive has been attributed to individual predisposing conditions such as cultural beliefs, knowledge, and skills^{5,6,7} as well as a lack of public awareness.⁸

This article will discuss educational efforts to address these predisposing conditions and to increase public awareness in countries with legislation in place. In an international overview of systematic reviews, authors reported that the completion rate of advance directives was not increased through the use of passive educational methods such as providing posters or videos; however, information shared in interactive sessions was an effective means of increasing the completion rate of advance directives.⁹ While pertinent for all age categories, older adults are a very important target audience for this information.

Internationally, the number of adults 60 years of age and older is increasing, “In absolute terms, the number of older persons has more than tripled since 1950 and will almost triple again by 2050.”^{10(p47)} More deaths occur in the older adult group than in

any other group. For instance, it is projected that in England in the year 2030, 86.7% of all deaths will occur in those 65 years of age and older.¹¹ These statistics demonstrate the importance of targeting older adults with advance directives education.

Resnick and Andrews¹² suggest that education concerning advance directives ought to begin in the community setting prior to older adults becoming critically ill or mentally incompetent. Intuitively, the need to address advance directives prior to a health crisis makes sense. A decision about advance directives takes a good deal of thought and discussion among health care professionals, significant others, family members, and friends and is best done when all parties are calm and composed rather than in a stressful, emergency situation. Health education specialists’ expertise and employment settings provide ample opportunities for health education specialists to play an important role in beginning this discussion.

While the role of health education specialists may differ by country, the areas of assessment, planning, implementation, and evaluation are reported as common domains for health education specialists from various countries world-wide.¹³ These programming skills are the basis for providing topical educational programming that is relevant to a target audience in a particular culture. In the United States, hospitals are the largest employers of health education specialists¹⁴ and hospitals receiving Medicare funding are mandated by 42 C.F.R. § 489.102 to provide advance directives education to the surrounding community.¹⁵ Thus, this employment setting provides health education specialists with an opportunity to address advance directives.

In the United States, health education specialists have been included in discussions of end-of-life care education. The Society of Public Health Educators (SOPHE), through its collaborative role with the Centers for Disease Control and Prevention, the Center for Practical Bioethics, and the Directors of Health Promotion and Education, brought health education specialists into the discussions of an on-line course currently in development on end-of-life care. This course addresses needs in a virtual community.¹⁶ Beyond the virtual community, health education specialists must consider collaborative relationships with organizations that provide services to older adults in order to access the older adult population.

Collaborative relationships will differ by location. Some examples include collaborative relationships

with directors of senior centers and directors of senior housing. These relationships would facilitate programming where older adults congregate and live. Engaging older adults in these settings with theory based programming gives health education specialists an opportunity to facilitate end-of-life care consistent with the beliefs of older adults in this large and growing segment of the world's population.

Background

Advance directives began as a response to the ability to extend life through measures such as mechanical ventilation and feeding tubes. Advance directives were intended to provide individuals with control over their medical care if they were unable to communicate their health care choices. The World Health Organization defines advance directives as,

“A mechanism by which a competent individual expresses his or her wishes should circumstances arise in which he or she no longer is able to make rational and sound decisions regarding his or her medical treatment. Usually ‘advance directive’ refers to orders for withholding and/or withdrawing life support treatments at the end of life, made by writing living wills and/or granting power of attorney to another individual.”¹⁷

As noted in the above definition, there are two types of advance directives, a durable power of attorney for health care and a living will. A durable power of attorney for health care is the legal appointment of one person (appointee) by another (appointer) to make medical decisions for the latter when he or she is unable to do so.¹⁸ For instance, if an individual became comatose, the person appointed with durable power of attorney for health care would make the medical decisions for that individual.

A second type of advance directive is a living will. A living will provides legal documentation “that states that an individual does not want medical intervention if the technology or treatment that keeps her or him alive cannot offer a reasonable quality of life or hope for recovery”.^{18(p441)} For example, an individual would state in a living will his or her choice not to be put on mechanical ventilation if there was no hope of ever getting off of the ventilator. While the World Health Organization's definition specifically focuses on withholding or withdrawing life supports, it is important to note, that a living will also provides an

individual with a means to communicate acceptable life sustaining medical interventions and under which conditions these interventions would be acceptable to that individual.

The legal status of advance directives varies by country. Whereas many Western European countries legally recognize advance directives, specific legislation varies by country. Belgium, Denmark, the Netherlands, Spain, and Switzerland have legislation to support the decisional power of an advance directive to direct patient care in an incapacitated patient. In Germany, while legislation provides for a decisional role in directing care, the designated health care surrogate can oppose the advance directive. France recognizes the decisional power of an advance directive in a capacitated patient; however, the advance directive becomes consultative once a patient becomes incapacitated. In England, legislation supports the decisional power of an advance directive, however, if a patient chooses to refuse treatment, this treatment must be “expressed unequivocally for the physician to comply.”^{2(p716)}

In the United States, the legal status of advance directives varies by state. For instance, in Michigan, a durable power of attorney is a legal document, but a living will is not. However, while a completed living will is not legally binding, it still provides family members and health care providers with direction in regards to treatment decisions.¹⁹ Family members are often called upon to make end-of life decisions. A living will decreases the burden on family members attempting to make medical decisions without knowing an individual's end-of-life preferences.²⁰

The importance of advance directives goes beyond legal issues. It is also important to consider the costs of end-of-life care both financially and as it relates to quality of life. Advance directives affect both of these in a positive manner. While not the purpose of advance directives, they have been reported to decrease the costs of end-of-life care²¹ and this is an important issue when considering the potential increase in health care costs due to an aging world population. In the United States, while only five percent of Medicare recipients die each year, just over 25% of Medicare health expenses are spent on care of recipients during the last year of life. This figure has remained constant over the past two decades.²² An increase in health care costs in the months before death was also reported in an international study.²³ Often these costs are a result of high tech treatment which has been reported to decrease quality at end of life. A recent study reported that the family members of patients cared

for in areas with high ICU usage reported lower quality of care when considering physical comfort, emotional support of the decedent, shared decision making, treatment of the dying person with respect and providing information and emotional support to family members.²⁴

In the United States, the 1990 Patient Self-Determination Act mandated that any institution in the United States receiving Medicaid or Medicare funding must provide information to all patients describing the patient's rights to make medical decisions and to establish a written advance directive. While this law has been in place since 1991, many older adults in the United States still do not have an advance directive in place. A recent national study reported that 54.3% of decedents had an assigned durable power of attorney for health care and 44.9% of decedents had a living will in place.²⁵ Even among the very old, advance directives are not consistently in place. Of community dwelling older adults between 84 and 100 years of age, 66% had a durable power of attorney for health care and 55% had a living will. Forty-one percent had both a durable power of attorney for health care and a living will.²⁶

Rates for advance directive completion in Europe also remain low. In a study of end-of-life decision making in six European countries less than five percent of those that died in Belgium, Denmark, Italy, Sweden, and Switzerland had a living will in place. Thirteen percent of those that died in the Netherlands had a living will in place at the time of death.²⁷

Completion of advance directives has been recognized as an international priority, especially for older adults. Yet, international statistics demonstrate that many of the dying have not completed an advance directive. Through application of the Theory of Reasoned Action, health education specialists can use their skills in program planning and evaluation to address deficits in knowledge and skills and can address attitudes in regards to completion of advance directives.

Increasing Completion of Advance Directives Using the Theory of Reasoned Action

The Theory of Reasoned Action can be applied to interactions between health education specialists and older adults. Although completion of an advance directive is often seen as an individual action, the Theory of Reasoned Action identifies the role of

subjective norms in the development of intent.¹² The decision to complete an advance directive is affected by individuals in the older adult's environment. This may include significant others, family members, friends, and health care providers. Application of this theory provides guidance in educational programming to increase completion of advance directives by older adults.

The Theory of Reasoned Action explains behavior by focusing on intention. If a person intends to do something, then it is likely that it will be done. Intention is affected by attitudes toward the behavior and perceived subjective norms, or what a person believes those significant others expect of him/her relative to the behavior. These attitudes and perceived subjective norms lead to the intent to follow through with a behavior; the end result is the behavior.²⁸ In the case of advance directives, when applying the Theory of Reasoned Action, health education specialists would be working toward changing the participant's behavioral intention to complete an advance directive.

Attitude Toward the Behavior

Behavioral beliefs and evaluations of behavioral outcomes

The first construct of the Theory of Reasoned Action is attitude toward the behavior. As Glanz, Rimer, and Lewis state, "Attitude is determined by the individual's beliefs about outcomes or attributes of performing the behaviors weighted by evaluations of those outcomes or attributes."^{29(p68)} Therefore, older adults who believe (1) they are capable of completing advance directives, (2) that advance directives are effective in meeting their needs, (3) that advance directives will have the outcome desired, and (4) that advance directives fall within their belief system, are more likely to have a positive attitude toward them.

Capable of completing advance directives

An individual's perception about their ability to obtain and complete an advance directive may impact their intention to complete an advance directive. Among a group of 51-70 year old individuals (N=109) that had not completed an advance directive, 28% shared that they did not know how to fill one out and 27% did not know where to get one.⁵ Health education specialists must be aware of where residents can obtain advance directive forms. In the United States free advance directives forms, as well as the instructions for each state, can be found at the

Caring Connections Website (<http://www.caringinfo.org/stateadownload>). Providing information on where to obtain an advance directive, directions or assistance with downloading, and information on how to complete an advance directive can support the development of a more positive attitude toward them and thus increase the likelihood that older adults will complete an advance directive.

Another educational issue that has the potential to negatively impact intention to complete an advance directive is the language commonly used in these documents. Older adults may not fully understand these concepts. A recent study tested older adults' knowledge of concepts related to treatments typically discussed in advance directives and the outcomes of treatment.³⁰ Misperceptions about treatment outcomes were common. For example, about half (46%) of the respondents incorrectly believed that a feeding tube prevents walking around or functioning independently and just over half of respondents (52%) did not know that a potential outcome of mechanical ventilation is permanent dependence on the ventilator.³⁰ This educational issue is intensified with low literacy seniors or in working with seniors with language barriers. Therefore, educational efforts must assure that older adults understand the terminology, treatment modalities commonly used at end-of-life, and treatment outcomes, if a positive attitude toward feeling capable of completing advance directives is to develop.

Advance directives effective in meeting needs

Education focused on individual needs and the role of advance directives in meeting these needs is also very important. Desiring to have a meaningful existence and wanting quality of life, are needs that have been demonstrated to influence completion of advance directives.⁶ Educationally, there are many ways to meet these needs.

Many individuals value autonomy as a means of self empowerment³¹ and empowerment is important in assuring that an individual is able to assure that their end-of-life experiences are dictated by their beliefs. Therefore, health education specialists can explain to older adults, who value autonomy, the way in which advance directives preserve their autonomy in end-of-life decision making, even after they no longer can verbalize their desires. Health education specialists may also encourage older adults to reflect on their personal definition of a "meaningful existence" and

"quality of life" and explore ways in which advance directives can assure that these personal definitions are reflected in advance directive documents.

Advance directives will have the desired outcome

The desired outcome of advance directives is that a person's end-of-life requests are respected. To ensure that this occurs, older adults must be encouraged to discuss their wishes with both family members and health care providers. A recent study revealed that 76.5% of participants with advance directives believed that their desires would be respected if they could not speak for themselves. However, only 11.8% had discussed their desires with their health care practitioners and 52.3% with family members.¹⁹ Without proper documentation and communication, it is unlikely that the completed advance directives will have the desired outcome.

Therefore, it is very important that older adults know they need to share their advance directives with health care professionals and that physical copies of the directives ought to be added to their medical charts. It is important that these discussions continue over time as end-of-life preferences among older adults may change.³² It is also important for older adults to understand that these changes are acceptable and they must be informed about how to make these changes based upon the laws that are in place. For instance, in the United States an advance directive may be changed at any time through verbal or written communication.³³ The ability to change advance directives allows older adults to have their desired outcome even if that outcome changes over time.

Advance directives and belief systems

Earlier it was noted that valuing autonomy was a motivator in completing an advance directive. However, health education specialists must be aware that individual autonomy is valued to greater and lesser degrees by various cultures. For example, in many Asian cultures, family is the focus, rather than the individual, and important decisions are made by the family as a group.^{7, 33} Therefore, when working with older adults from Asian cultures, it is important to include family members in discussions about advance directives, as the individual may not be accustomed to making such decisions alone.³⁴ Including family members may also facilitate compliance with laws that may be contrary to cultural norms. A recent study in the United States reported that, "almost all durable power of attorney for health

care statutes anticipates the appointment of a single agent rather than a family unit.³¹ Additionally, national or state law may dictate one family member be the decision maker, for instance in the state of Alabama, the default decision maker is the spouse,³⁵ however in some cultures the oldest son may be responsible for making decisions. Making decisions together allows for respect of culture as well as complying with the law.

Religious beliefs are important when an individual considers acceptable end-of-life care. Health educators are encouraged to familiarize themselves with acceptable end-of-life care as viewed by the major world religions. Bulow et al³⁶ provide an overview of the various world religions and discuss the acceptance of various end-of-life interventions.

In addressing religious issues, it is important to emphasize that the role of advance directives is not to limit care, but to ensure that the individual's desires for end-of-life care are honored. Some religions encourage all medical care available. For instance, "the Greek Orthodox Church rejects every death resulting from human decisions as being an insult to God and condemns as unethical every medical act that does not contribute to the prolongation of life."^{36(p425)} Advance directives can be created that communicate the desire to receive all medical care. A living will can list the individual's wish to have all life-sustaining treatments. A durable power of attorney can be appointed who will see to it that these wishes are respected.

Subjective norm

Normative beliefs and motivation to comply

The second construct associated with intention is perceived subjective norm. The concept of subjective norm is broken down into the normative beliefs of others and the motivation to comply with these beliefs.²⁸ For example, do the older adults perceive that their significant others, family members, friends, or health care professionals believe that they ought to complete an advance directive? If this is the perception, then they are more likely to complete an advance directive. Secondly, how motivated are they to comply with these beliefs? For example, are they overly concerned the expression of individual wishes are contrary to the collective values of the family, potentially resulting in tension among family members? If so, this may serve as a significant barrier against the completion of an advance directive.

In keeping with the Theory of Reasoned Action, it is the person's desire to do what he or she believes the significant others would want done that affects intention. Thus, educational efforts to address subjective norms ought to focus on enabling the older adult to discuss the idea of advance directives with significant others. Health education specialists may act as facilitators of the dialogue between the older adult and significant others.

Starting that discussion can be difficult for many older adults, however, reflecting on the experiences of others has been demonstrated to be effective in engaging older adults in end-of-life planning.³⁷ Health education specialists can encourage older adults to reflect on their own personal experiences with end-of-life care with friends and family. What they found acceptable and what was felt to be difficult can be discussed. Encouraging older adults to share these reflections with significant others may be beneficial to older adults' understanding of how their significant others and health care providers feel about the idea of advance directives. Discussing current events, current popular books, or popular movies can also be helpful in beginning the end-of-life discussion with significant others. For instance, in the United States, the seven year battle between Terri Schaivo's husband and parents brought the discussion of advance directives into the home of many Americans through the news media. Because many Americans can relate to this case, it may be helpful in starting a conversation during educational sessions in the United States.

In addition, the Center for Practical Bioethics suggests beginning a conversation to discuss end-of-life decisions with basic questions that focus on when, where, and with whom an individual will have advance directive conversations.³⁸ The "with whom" is an important area to address. With whom do they feel comfortable, whose insight is valuable to them, and who do they believe would best serve their interests? It may be beneficial for health educators to invite both older adults as well as their chosen significant others to advance directive community education programs.

Summary

Health education specialists play an important role in addressing health challenges throughout the lifecycle. Receiving appropriate end-of-life care is an important internationally recognized challenge that can be addressed by health education specialists through community education programs. By applying the

concepts of the Theory of Reasoned Action, health education specialists can develop programming aimed at increasing the intention of older adults to complete advance directives.

In light of the expanding population of older adults throughout the world, additional health education programming and research must address the need for this population to complete advance directives. Such programming and research should address the application of the Theory of Reasoned Action when developing instruments measuring older adults' knowledge, attitudes, and skills in the completion of advance directives. In this way, health education specialists take a crucial step in assuring end-of-life preferences are met.

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