

End-of-life decisions: physicians as advocates for advance directives

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Physicians have a unique role in supporting patients and families throughout their lives; their expertise is called on not only in life, but also at its end. This study was designed to determine the effect of an individual's age, gender, and attachment to the decision maker with regard to life support choices. A total of 151 subjects completed the researcher-developed instrument. Results suggest that the age of patients is significantly related to the life support options chosen. Specifically, the greater the age of the patient, the more likely a less vigorous life support alternative was chosen. Gender and attachment had no effect on the level of care chosen. Study participants also identified reasons for selecting a particular life support choice for each case. The most common reasons given for a close relative centered around quality-of-life issues. In situations involving a nonrelative, life support decisions were likely to be made using the principle of best interest. The primary care physician has a unique opportunity to initiate discussions about life support issues with patients and families. These decisions must be framed in the context of individual patient expectations and desires throughout the life span.

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The role of the physician in life support decisions has become more uncertain as society demands more patient autonomy and the courts erode the role of clinical decision making.¹ Kennedy² states that physicians have no greater expertise than laymen in dealing with ethical issues. However, while physicians may not have more expertise, it can be argued they have greater experience, as they deal with death on a regular—and sometimes daily—basis.

The physician's traditional role in a patient's death has been to provide comfort, offer information, and carry out the patient's wishes. For those wishes to be clearly elucidated, it is essential that the physician take the initiative in discussions of advance directives, ensuring they are informed and realistic.³ The ideal time for such a dialogue is the first office visit, during the history taking. Once the topic is broached, further exploration can take place as the patient's preferences for feedings, antibiotics, blood transfusions, and cardiopulmonary resuscitation are defined.⁴ Indeed, it is incumbent on the physician to hold such discussions while patients are still competent and to urge them to choose a surrogate, as well as indicate precisely how much discretion the surrogate will be allowed.^{3,5} If physicians do not take the lead in promoting advance directives, they will leave a window open for hospitals, families, and the courts to challenge the patient's true wishes.

Until recently, patients have been willing to comply with the "doctor knows best" status quo. However, traditional paternalistic attitudes are being replaced with a philosophy of shared decision-making between physician and patient, and often, family members.⁶ In the past two decades, society has placed an increasing emphasis on patients' rights and the concept of autonomy. Autonomy has, at its roots, principles of self-determination and self-governance in all situations.⁷ A dilemma arises, however, when the patient is viewed as incompetent to make autonomous choices regarding care and treatment.

Typical bioethical models focus on patient autonomy as the central element of the paradigm. Crabtree and Caron-Parker⁸ enumerated three models from which the foundation of current ethics is derived. First, the "medical model" assumes that the acutely ill patient can be cured or can compensate for any physical losses incurred due to the illness. Second, the "contractual model" mirrors any other business transaction, in that the patient is assumed to voluntarily comply with the actions of the healthcare provider. Third, the "humanist model" assumes that individuals act as rational free agents, able to choose medical services in their own best interests.

Current researchers are investigating care and justice considerations that are used in ethical dilemmas when one makes medical decisions for oneself or one's family as opposed to other people.⁹ This research contributes to the knowledge base regarding reasons behind decisions, but it does not address whether the decisions would be the same for patients of different ages or across age groups given the same circumstances. Additionally, the role of gender in decision-making is not addressed.

Review of literature

All healthcare institutions that accept federal funding are now required by the Patient Self-Determination Act (PSDA) to ascertain on admission if a patient has an advance directive. The PSDA applies not only to hospitals but also to nursing homes, hospices, and home health agen-

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cies. These agencies are also mandated to implement policies regarding recognition of an advance directive, as well as to educate their staff and the community at large about advance directives.¹⁰

Characteristics of advance directives and their use

One of the assumptions of the PSDA is that patients will execute an advance directive if they are given enough information and encouragement.¹⁰ Despite a federal law and community education efforts, however, the use of advance directives remains limited. In 1989, before the PSDA, Zweibel and Cassel¹¹ reported only 4% to 15% of people in the United States had some type of advance directive, and most of them were older adults. In 1995, that number was only 20%, a minimal increase by even the most generous standards.⁴

Another study indicated that while the elderly were willing to discuss advance directives, advance directives were still infrequently used. More important, even when the person had completed an advance directive, that person's physician remained unaware of the directive's existence.¹² Two preliminary studies of people over age 60 years indicate that advance directives are not being used, even though the study participants had high levels of familiarity with and understanding of them.¹⁰ An important finding from the same study is that people who attend an instructional meeting and are given assistance with preparation are more likely to complete an advance directive.¹⁰

There are some barriers to implementation of advance directives. For example, completing an advance directive requires decisional capacity and simulates future hypothetical medical situations that are uncomfortable to face.^{13,14} The process forces a patient to contemplate the end of life, an experience that can be unsettling.

Because the response to envisioning one's own death is often emotional, even when an advance directive is completed, it frequently will contain only vague, ambiguous, or general preferences rather than specific treatment choices.³ Even if choices are stated clearly, it is still unre-

alistic to believe the advance directive can anticipate all future decisions. Lo³ has suggested that for such directives to be meaningful, a series of mutual discussions must take place between the patient and physician—and perhaps the family as well—rather than relying on a single declaration by the patient.

Barriers to preparing an advance directive

Most people, especially the elderly, are comfortable deferring medical decisions to their physicians. A natural outgrowth of this idea is the belief that the physician will take the initiative in discussing an advance directive if one is needed.^{10,12} Other reasons cited for not preparing a directive include believing the issue is only relevant for people who are older or in poor health, and perceiving barriers such as cost, availability of witnesses, or a notary.^{10,12} The most frequently cited reason for not executing an advance directive is the expectation that others, presumably family and physicians, will handle the issue when the time comes. This attitude reflects a widespread confidence that people can rely on others in crisis situations.¹⁰

The most important implication for research and public policy is the least-cited barrier to use: lack of knowledge or sensitivity to the topic.¹² People are obviously cognizant of the issue, yet still find reasons to put off preparing a directive, expecting family to perform as surrogates if necessary.

End-of-life decisions

Physicians and patients' families commonly base end-of-life decisions on previous statements made by the patients, inferring from these that they are either making a substituted judgment (trying to act in accordance with what the patient might have wanted) or acting in the patient's best interest (behaving in accordance with what the individual feels is best for the patient).¹⁵ In reality, the specific situation is as much a part of the context of the decision as are the values and character traits of the decider. To assume that one can decide in any given situation what a patient would want, based on past behavior, assumes an unre-

alistic degree of consistency in the person's life and previous decisions.³ It is preferable for a patient to complete a directive in as specific terms as possible, and then for physicians and family to follow it, to guarantee contiguous autonomy.

Estimates of treatment consistency with regard to patient decisions and advance directives range from 33% to 75%.¹⁶ Disturbingly, this consistency was less likely to occur when a directive was present in the medical record than when it was absent.¹⁶ Several factors can lead to the directive not being followed.

Providers are frequently unaware of the existence of directives. Further, the provider may believe that the initial preference was too restrictive to allow for care deemed appropriate at the time. Alternatively, the treatment chosen may, in the provider's view, afford little benefit to the patient. Finally, families may contradict the advance directive.¹⁶

Because incompetent patients are four times more likely to receive treatment inconsistent with their wishes, it would appear that appointing a trusted person as proxy would be a better way to ensure continued autonomy.¹⁶ Without such a proxy, legal battles often ensue, putting an unprepared court system into the role of making patient care decisions. Because many of these factors that influence end-of-life care are not consistent with actual patient wishes, this study was designed to explore the reasons for such discrepancies.

Purpose of the study

The purpose of this study was to determine if the patient's age, gender, and level of attachment affected the outcome of a medical decision made for a particular patient. Specific questions that guided the research were the following:

- Does the level of life support chosen decrease as age of patient increases?
- Does patient gender influence the choices made on behalf of that patient?
- Does the likelihood to choose more aggressive forms of life support increase as the level of attachment to another increases?

Your elderly parent has a medical condition that has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. Because there is no advance directive, you are asked to complete medical instructions for use in the event that your elderly parent stops breathing or the heart stops beating. Check only one of the following life support options for your parent.

- ☐ Full cardiopulmonary resuscitation
- ☐ Cardiopulmonary resuscitation and drugs, no intubation
- ☐ Drugs only, no cardiopulmonary resuscitation
- ☐ Nutrition, fluids, pain medication, and comfort measures only

- ☒ What is the age of your parent?
- ☒ Is your parent male or female?
- ☒ What factors did you consider when making your decision?

Figure 1. Sample vignette. The seven vignettes used in this study were assessed for face validity by three physicians and three registered nurses.

Methods

Previous research has focused on medical practitioners' life support choices or patients' choices for themselves. This study focused on individuals' choices for family and self as well as for people they do not know. Additionally, qualitative data regarding the rationale for the choice with regard to age, gender, and life support was collected in an effort to determine if ethical constructs underlie these critical decisions.

The present study employed a combination of two methods: correlational and descriptive. The study sought to determine the relationship between age, gender, and type of life support decision chosen. Relationships between these factors and level of life support chosen were described and examined in terms of patterns, trends, and common themes. Other factors were discovered by asking open-ended questions regarding the rationale for choices made.

Instrument

Demographic questions were used to obtain background information on the respondents and to provide information on family characteristics, such as composition, developmental stage, and roles. Although previous literature has not highlighted demographic variables as influ-

ences on resolution of ethical dilemmas, the current study of subjects in a family context did elicit different relationships.

Vignettes

Respondents were presented with seven different vignettes (situations) in which the age and relationship of the patient varied. The vignettes were researcher-developed to reflect a consistent medical diagnosis and prognosis across all situations. The seven situations involved a spouse, a child, an elderly parent, an elderly neighbor, a coworker, a stranger, and one's self. *Figure 1* shows an example of one of the vignettes used in this study.

The language of the life support options was adapted from Malloy and colleagues.¹³ Their research has shown that the descriptive language used can significantly influence the level of life support chosen. The language presented was clinically accurate and realistic but not clinically obscure or negative.

The nonprobability sample (N = 151) consisted of people 18 years of age and older who were drawn from a large metropolitan area in the Midwest, a retirement village, and a land-grant university in the Midwest. Average age of the respondents was 38 years (*Table 1*). Most (72%) were female, and more than half (54%) were married. Respondents were

Table 1
Sample Characteristics
(N = 151*)

Characteristic	%
☒ Highest education level attained ☐ High school/some college ☐ College degree ☐ Graduate/professional degree	 57.6 29.1 13.2
☒ Ethnicity ☐ Caucasian ☐ African-American ☐ Native American ☐ Other	 86.1 7.9 4.6 1.4
☒ Gender ☐ Male ☐ Female	 28.5 71.5
☒ Occupation ☐ Business/professional ☐ Office/technical ☐ Student ☐ Other	 33.1 27.8 33.8 5.3
☒ Marital status ☐ Married ☐ Never married ☐ Divorced ☐ Other	 54.3 29.1 9.9 6.7
*Mean age, 38 years.	

primarily white (85%), had some college education (50%), and were typically employed in business or technical occupations (61%).

The subjects were administered the instrument, instructions were given, and questions were answered as necessary. All participants received a survey booklet and a separate sheet of life support definitions to assist them in responding to the vignettes.

Results

Correlational studies were completed to determine variable interrelationships. The relationships that were addressed included data measured either at an ordinal or an interval level. The relationship of qualitative factors and life support choices was determined using thematic analysis.

Table 2
Correlation of Patient Age with Life Support Option

Situation	Correlation	P value
Spouse	.3146	.000
Child	.1106	.098
Parent	.2988	.000
Neighbor	.2183	.005
Coworker	.1138	.089
Unknown	.0591	.255
Self	.2686	.001

Table 2 indicates that the age of a spouse, parent, neighbor, and self were all significantly related to the life support option chosen. The greater the age of the patient, the more likely a less vigorous life support alternative was chosen. In contrast, in situations involving a child, coworker, and a stranger, decisions for end-of-life care did not significantly correlate with age. Respondents were also asked to identify a gender for each patient in the seven scenarios. In all seven situations, gender was not a significant factor ($P < .05$) in the chosen form of life support.

Before data collection, researchers hypothesized that attachment would correlate highly with the level of life support one would choose for another, with closer relationships resulting in more complex or heroic life support measures. Although no statistically significant relationship was found in the choice of life support for others based on attachment ($P < .05$), certain qualitative factors regarding personal feelings emerged as important in relation to choices.

Qualitative factors

In all, 151 respondents were asked to make a life support choice for each of seven different scenarios, for a total of 1057 responses. Additionally, respondents were asked to list factors that shaped their particular decision in each case. From this large pool of potential responses, 14 main themes emerged as the basis for the life support choice (Figure 2).

The most common reasons given for

choices involving a close relative (for example, elderly spouse, elderly parent, child, or self) related to quality-of-life issues. For a nonrelative, life support decisions were likely to be made using the principle of best interest.

For most responses, there was a presumption that the wishes of the patient were clearly known to the decider. This logically assumes that families are having conversations about end-of-life issues and personal preferences. However, neither current research nor anecdotal reports support this view. More commonly, family members tend to bicker among themselves about life support options, with each member claiming to know what the patient wants. This often occurs at a time of great personal strain on the entire family, and the life support choice becomes the stage on which feelings of guilt and shame—as well as issues of control—are acted out.

Comments

Based on the prevailing attitudes of the study participants, the results suggest that subjects are less likely to choose full life support measures for older individuals. These results are consistent with other research in which less aggressive support was chosen for older adults, often at odds with patient preferences.¹⁶ Therefore, it may be in the best interest of an elderly patient to have his or her personal physician serve as a first-line advocate in promoting views regarding end-of-life issues and in defining personal choices for successful aging.

The process of aging and of defining

- ☐ Person had a long life
- ☐ No potential for quality of life
- ☐ Do not want the person to suffer
- ☐ Love/personal feelings
- ☐ Money
- ☐ Philosophical/moral issues
- ☐ Religious beliefs
- ☐ Do not want to be a burden to others
- ☐ Same decision I would want for myself
- ☐ Knowing that is what they would want
- ☐ Doctors can be wrong/miracle
- ☐ Do not know the person or their wishes for certain
- ☐ Physician stated there was no chance for recovery
- ☐ Nobody to care for them if they live

Figure 2. Qualitative factors in life support decisions.

quality-of-life experiences that go along with it are personal. For some, especially if one believes in the media's advertising campaigns, it may mean imitating activities and attitudes of younger people. Glamorization of geriatric athletes, 80-year-old sky divers, and fitness-oriented elderly couples make good press. However, the truth is that many older people define successful living in terms that do not include any of these images. Instead, many people, as they grow older, describe quality of life in terms of performing as good spouses, functioning as loving grandparents, contributing to the well-being of their families and communities, or serving as faithful friends. The joy of living may be defined as appreciating art, literature, or music—not simply in performing youth-oriented activities. Physicians are in a good position to understand the wishes of their older patients in the rich context of their lives, and to honor them by helping them make difficult end-of-life choices.

The busy physician can help patients to get information about advance directives, as well as assist in documenting

patients' end-of-life wishes through such directives. This process can be handled in a stepwise fashion using office resources. The waiting room is a good place in which to start. For example, advance directive information in the form of flyers and brochures can be made available for patients, along with other health-care literature and magazines. State-specific guidelines may help clarify rules for the specific location of the physician's practice.

The next step would be to have a medical assistant or nurse ask the patients at check-in if they need to talk about completing an advance directive, or if they need to update one already on file. Requesting copies of these documents from others who have them (for example, attorneys and other physicians) is part of this process for each patient. These copies can be included in the medical record. A colorful sticker on the chart can indicate this has been done. Since the inception of the Patient Self-Determination Act in 1990, this strategy is used in all facilities that accept Medicare funding, so patients are becoming accustomed to the question. Properly trained office staff can assist patients and family with completing the advance directive or can make appropriate referrals (usually to the hospital social work department). The final level of involvement would include the physician, who would be able to answer more in-depth questions about end-of-life management.

The primary care physician has a unique opportunity to initiate discussions about life support issues with patients and their families. These decisions must be framed in the context of individual patient expectations and desires concerning quality-of-life definitions as they age. If a health status change occurs, it is important for the physician to open discussions regarding the implications of illness on lifestyle and end-of-life support. Advance directives must clearly document the wishes of the patient as a guide for caregivers and family members. The primary care physician can be an advocate of such wishes only if they are clearly understood. Because of the potential for misunderstanding or well-meaning errors in decid-

ing what a patient actually desires for end-of-life care—even in the most supportive situations—it is critical that physicians elicit and document this information in a carefully crafted advance directive.

In an atmosphere of honesty and trust, older adults can make informed choices that will allow their desires to be carried out with dignity and grace. Physicians who successfully participate in this process can feel the satisfaction of serving both the physical and emotional needs of their patients and their families when making these decisions.

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