

EPECTM-O

Education in Palliative and End-of-Life Care for Oncology:

Cultural Considerations

When Caring for

African Americans

Module 13-AA:

Advance Care

Planning

Abstract

Advance care planning and completing advance directives can often mitigate turmoil at end-of-life, as families and providers are trying to determine what medical care and treatment a non-communicative patient may have wanted in a variety of clinical circumstances. In this module, the advance care planning process is described, as well as how and why the process may be undertaken differently among racial and ethnic populations with differing cultural perspectives. The various advance directives in current use are defined, together with their usefulness and drawbacks.

African Americans' shared experiences, beliefs, and values may raise barriers that influence their willingness to participate in advance care planning. Accordingly, African Americans engage in advance care planning differently from Whites for a variety of reasons. These include differences in spiritual and cultural perspectives; differences in knowledge of, and familiarity with, advance directives; and communication disparities between healthcare providers and African American patients that do not pertain with White patients. These differences can be appropriately addressed by understanding: the importance of advance care planning, the desirable outcomes that advance care planning can bring about, and culturally sensitive approaches that incorporate respect for the patient and family.

Barriers to advance care planning among the African American population are discussed, as are evidence-based interventions to increase engagement in the process of advance care planning and completion of advance directives. A stepwise process for advance care planning is presented, along with practical guidance on how to incorporate it into routine office visits. The steps presented include the appropriate introduction of the topic, semi-structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the plans and directives, and application of the wishes when needed. Finally, there is material on how to aid the patient and family with practical planning at end-of-life which is analogous to the process of advance care planning.

Key Words

Advance care planning, advance directive, advisory document, durable power of attorney for health care, end-of-life care, honoring patient wishes, living will, personal preparation, pitfalls, proxy, statutory document, structured discussion, validated advance care planning worksheet

Objectives

At the completion of this module, the participant will be able to:

- Define advance care planning and explain its importance and benefits, as well as its drawbacks and limitations.
- Describe the differences in attitudes and behaviors between and among African Americans and Whites as they engage in the advance care planning process.
- Discuss ways in which cultural traditions and spiritual beliefs play a vital role in the decision-making process.
- Describe barriers to completion and implementation of advance directives—especially in the African American rural and urban communities—and ways to overcome them.

- Describe the steps of the advance care planning process and the roles of the patient, health care proxy, family, and healthcare providers.
- Utilize planning to help the patient put affairs in order and complete an advance directive.

Definitions

Advance directives: Legal documents that seek to obtain prior guidance from the patient for his or her health care. There are two categories:

- Instructional directives, such as a living will, which allows an individual to provide preferences for care. These might include requesting no heroic measures (for example, feeding tube, ventilator, respirator, CPR, antibiotic therapy) under certain circumstances where prognosis is poor. Conversely (in the same scenario), they might specifically request continuation of aggressive interventions.
- Directives that designate a health care proxy, a surrogate decision-maker for the patient, such as a Durable Power of Attorney for Health Care (DPOAHC). A DPOAHC also may be referred to as a health care proxy, health care agent, attorney-in-fact, or surrogate. It allows a person who is so designated to make decisions on behalf of the patient if the patient were incapacitated.¹

Best Interest Standard: When the surrogate decision-maker cannot in good faith ascertain whether the patient, when competent, would have consented to a proposed course of treatment, he or she must determine that the treatment is in the patient's best interest before giving consent. Factors that should be considered in determining whether medical treatment is in the best interests of the incompetent individual include:

- The patient's present level of physical, sensory, emotional, and cognitive functioning;
- The various treatment options and the risks, side effects, and benefits of each of the options;
- The life-expectancy and prognosis for recovery, with and without treatment;
- The degree of physical pain resulting from the medical condition, treatment, or termination of treatment; and
- The degree of dependency and loss of dignity resulting from the medical condition and treatment.²

Medical directive: A set of instructions based on likely scenarios of illness, goals for care, and specific treatments, combined with a general values statement. It is also combined with a health care proxy designation section.³

Substituted Judgment Doctrine: A legal doctrine that allows a surrogate decision-maker to attempt to establish, as accurately as possible, what decision an incompetent patient would make if he or she were competent to do so.⁴

Values history: A statement of values regarding health care in life-threatening illness situations. A personal letter also may be used to communicate these preferences.³

(See Appendix 1: Advance Care Planning: The Law and Policy)

Case Study Vignette

Mrs. Washington, a middle-aged African American woman, has just completed an office-based infusion of chemotherapy for her cancer. Her husband is with her in the room. The oncologist and the infusion nurse engage the patient and her husband in an interactive discussion about advance care planning in response to questions from Mrs. Washington.

The video can be accessed by clicking on the following link:

<http://www.youtube.com/watch?v=fsBI4pneoSo>

Introduction

The Importance of Advance Directives

Advance care planning is the process of making decisions for future medical care while the patient is competent. This gives the patient the ability to make choices now, in the event that the patient is unable to make his or her own decisions later.

The importance of advance care planning is underscored by the turmoil families and providers may encounter when decisions are to be made without knowing the patient's attitudes, preferences, and beliefs about care at the end-of-life. Media attention given to several difficult cases has highlighted the importance of patients and families talking about death and dying and planning ahead.

In spite of the importance of advance care planning many people reach the end-of-life without engaging in the process. This is true of the American population generally, and of African Americans in particular, and leaves their families or providers in the dark about their preferences for treatment.

The Patient Self-Determination Act

Congress passed the Patient Self-determination Act in 1991.⁵ The law requires that health care providers, staff, patients, family and community be provided with education concerning advance directives. The purpose is to give a patient greater autonomy in choosing treatment options in the event of serious illness, even if the patient becomes unable to express his/her care treatment preferences. Self-determination in advance can lessen the burden on the family faced with decision-making for an incapacitated loved one. The Patient Self-Determination Act requires that health care facilities receiving federal funding inform all patients of their right to complete an advance directive. Unfortunately, many patients enjoy this right without its benefits. Most facilities have put procedures in place to meet the letter of the law by including information in the admission process; however, since the law does not require a discussion with patient or family, this information and thereby the goal of the law is compromised.

Completion rates for advance directives

The U.S. Department of Health and Human Services (DHHS) reported in 2010 that advance directive (AD) completion rates for residents of a nursing home are 75 percent for Whites, 41

percent for Blacks, and 50 percent for Hispanics. For community dwelling elders receiving home health services, the rates were 42 percent for Whites, and 12 percent for Blacks and Hispanics. Rates in hospice are 93 percent for Whites and Hispanics, and 79 percent for Blacks.⁶

Even lower rates are described for hospitalized, medically-ill populations. This suggests that the occurrence of a major medical event may not be the best time for advance care planning.⁷

“No one brought it up.” is the most common reason ADs don’t get completed.⁸

Barriers to Completion of Advance Directives Among African Americans

Why do smaller percentages of African Americans complete ADs, compared with Whites?

The reasons are varied:

- lack of familiarity with advance care planning (ACP) and ADs among African Americans,
- cultural differences in the approach to end-of-life planning among African Americans compared with Whites,
- spiritual beliefs that may be in direct conflict with ACP,
- communication disparities between healthcare providers and African Americans compared with Whites,
- institutional barriers,
- mistrust in the medical system on the part of African Americans based on a long history of inequitable and at times unethical care,
- difficulty in understanding AD documents that are generally written at a health literacy level far above that of the average adult, and, among some individuals, superstition concerning the discussion of end-of-life care.

Lack of familiarity

Numerous studies have shown that African Americans are not familiar with ADs.^{9, 10} Though conversations about advance directives have been ongoing, for many racially and ethnically diverse populations this is a new topic. Yet, studies indicate that, when informed about the option of expressing end-of-life preferences, African Americans do complete advance directives.¹¹ Still misperceptions persist among some African Americans that discussions of end-of-life care are really about physician-assisted suicide and euthanasia.¹²

Cultural differences

Cultural differences may contribute to the disparity in AD completion rates between African Americans and Whites, some studies have found. For instance, autonomy may be less important among African Americans while it is highly valued among the predominant culture in America.

Daalman found in an exploratory study that African American elders preferred a style of “deferred autonomy.” They are autonomous in their day to day living, but prefer to postpone involvement in future care decision-making.⁹ It is important to note that African American elders remember the days of segregation and many have experienced harm and had their rights violated for expressing their views and opinions. Some older adults have been socialized and learned how to cope without free expression of their opinions and preferences. Decision-making may not look the same for them as it does for others who do not share this past history, even though the social milieu has changed.

Others point out that African Americans prefer a family and community-centered process for decision-making. They may not see the need for written advance directives, believing that family members know their wishes.⁸ Kwak reported that in elder focus groups of all races, there was a preference to identify one surrogate decision-maker who would ultimately be in charge of making decisions should they be unable to do so. The degree of autonomy for surrogate decision makers preferred by the elders varied widely between and among different racial and ethnic groups.¹⁰

African Americans are also more likely to prefer life-sustaining therapy, and to think that this preference precludes involvement in Advanced Care Planning.^{8, 9, 13, 14} Generally, patients and families understand ADs as a way to limit interventions rather than a means to request further treatment.

Spiritual beliefs

Understanding the importance of spirituality and faith to African American patients and their families is essential to improving end-of-life care. Rich traditions within the African American community are tied to religious and spiritual beliefs and practices that reflect a view of death as a “welcomed friend.” Death may be seen as integral to the transition from an earthly to a heavenly existence. “Going home” or “Home going” is consistent with the notion that death is a transition rather than a final state.¹⁵

The time leading up to death may involve significant struggle. Some African Americans believe that pain and suffering are to be endured as a necessary part of spiritual commitment, and not avoided. Pain was sent by God to test one’s faith and therefore it is to be endured.¹⁵ These values can conflict with health care professionals’ views about care at the end of life and advance care planning.

Some African Americans believe that only God has the power to decide life and death, and that God’s will is the most important factor in recovery from illness. African Americans are more likely to believe that a miraculous healing may occur.¹⁶ Engaging in advance care planning may be perceived as an act of distrust in God.¹⁷ Planning for end of life may be equated with giving up hope, or giving up on God.¹⁸ Prayer and reliance on God may take precedence over the completion of ADs.

Communication disparities

Patients expect providers to initiate the topic of advance care planning.

Many physicians fear that discussions about prognosis will cause harm to patients and families: they will lose hope, become depressed, or deteriorate further physically. African Americans are at an additional disadvantage, as studies of communication between physicians and patients from different races suggest that communication is often less interactive, with less explanation of medical condition, test results, and treatment options, less shared decision-making, and a lack of discussion regarding treatment alternatives in general, and specific alternatives such as hospice.^{12,}

¹⁹

Several studies now show that patients and families of all races and ethnicities actually want physicians to be open and honest with them about diagnosis, prognosis, and treatment effects and side effects. It has also been shown that these discussions do not cause increased distress in patients and families, but rather increase patient and family understanding of the disease, decrease distress, increase the trusting relationship with the provider, and increase the confidence of the surrogate in their ability to predict patient preferences.²⁰

Lack of Trust

Bergman-Evans pointed out that 75 percent of African Americans are in favor of advance directives, yet only 25-30 percent follow through with preparing documents.²¹ Why the disconnect between preference and action? African Americans know that they can be treated differently in the health care system, and that at times they have suffered historical injustices in receiving medical care in the research context. Many suspect that, if they fill out an advance directive, they will not receive appropriate care, and could receive inferior care, or no care at all. These fears make many African Americans suspicious of ADs.

African Americans also doubt that ADs will be honored, and perhaps with good reason. Several investigators have found that Whites are much more likely than African Americans to have their preferences for end-of-life care honored, whether the preference is for comfort care or aggressive care. Loggers et al found that many African Americans who had documented end-of-life care discussions and Do Not Resuscitate (DNR) orders in place were not protected from aggressive interventions, while many African Americans who wished to have intensive care did not receive it.^{22, 23}

Difficulty in understanding ADs

Although African Americans' are able to understand ADs as well as Whites, they tend to have a different point of contact with the health care system, which is where most patients and families learn and engage in conversations about ADs. The difference in access to information suggests, in some studies, that African Americans have less baseline knowledge of ADs than Whites. A lack of access to culturally and linguistically appropriate information and forms is also problematic.¹⁸ Most valid forms made available are written at an advanced grade level that is not

easily understood by the average adult. Patient education materials are thought to be most comprehensible when written between the 4th and 6th-grade reading level.²⁴

Institutional/legal barriers

All 50 states recognize either Living Wills and/or Durable Power of Attorney for Health Care (DPOAHC). Most also recognize advisory documents such as the Five Wishes form. A minority of states require that the form must be notarized while witnessed. A requirement to notarize ADs places additional burdens on individuals who already have limited access to these documents.¹⁸

Other problems with advance directives at large

The Agency for Healthcare Research and Quality (AHRQ) reports that fewer than 50 percent of severely terminally ill patients had an advance directive in the medical record. Only 12 percent received input from a physician in developing an advance directive. For African Americans, who have a greater likelihood of not having an identified primary care provider than Whites, this percentage may be even lower. Sixty five to 75 percent of physicians were unaware that their patient had completed advance directives.²⁰ ADs are often vague, can be difficult to apply in specific clinical situations, and often are avoided until the patient is hopelessly ill and death is imminent. Also, family conflict sometimes can arise and may create difficulties in following the ADs expressed by the patient.²¹

Numerous studies have also looked at the concordance between a surrogate's perception of the treatment preferences of the people for whom they were acting that did not have advance directives, and have found disparities, from no greater agreement than chance occurrence (50 percent) to 75 percent concordance. However, even in the presence of existing advance directives, concordance was not necessarily improved.²⁵ When asked about their patients' preferences for care, physicians' answers, even primary physicians with a longstanding relationship with the patient, had very poor agreement with patients' expressed wishes for care at the end of life.²⁶

Importance of Advance Care Planning

Why engage in Advance Care Planning?

Advance care planning gives patients a voice and empowers them to make decisions about their care should they become unconscious or unable to communicate their wishes.

Several studies have shown that completion of ADs is associated with less aggressive care at the end of life and also with earlier admission to hospice.²⁷ The longer the care in hospice beyond one week, the better the patient's quality of life (QOL) and the better the caregiver's bereavement course. Aggressive care at the end of life has been shown to diminish QOL for patients without lengthening the patient's life. It is also associated with worse bereavement outcomes for family members, including worse self-reported health, more regret, worse physical functioning, worse mental health, and worse overall quality of life.^{28, 29} Surrogates who can rely on ADs of their loved ones report decreased stress around decision-making.³⁰

Caregivers report that the stress of deciding to withdraw treatment from a loved one is “the worst stress they have had in their lives,” and objective measures of stress indicate it is worse than dealing with your house burning down. While the stress lingers beyond six months, it lessens over time.³¹ Surrogate stress is lowered in the setting where ACP has taken place.^{21, 29, 31}

In a mortality follow-back survey, Teno reported 78.8 percent of those who died in the nursing home, hospital, or home had an advance directive, which was associated with less likelihood of having a feeding tube, or of having used a respirator, in the last month of life. Those without ADs were more likely to report concerns with physician communication and with being informed about what to expect.²⁷

Camilla Hudson’s essay “Advance Care Planning – A Family Caregiver Perspective”³² poignantly portrays how difficult it can be to discuss these issues and ascertain the wishes of a loved one for end-of-life care without the benefit of advanced directives. She relates her experiences trying to encourage her ailing father to discuss his wishes with her, and how—after a long process of negotiation—he finally opened up about his wishes. In the end, the anxiety she felt as his surrogate decision-maker was finally resolved. In reviewing a plain language advance care planning document with him, she describes how the process “gave him a sense of control and made him feel that the entire process was conducted on his own terms... This type of empowerment was especially important to my father who, as a proud African American man, had always been the decision-maker for himself as well as his family.”

Effective Interventions to Increase Engagement in Advance Care Planning

Several literature reviews suggest that informative interventions alone (for example, giving patients written information) are ineffective. On the other hand, combining informative interventions with interactive interventions (including assistance with form completion) over the course of time increases the effectiveness of advance care planning.^{7, 33, 34, 35, 36} The intensity of interventions influences the rate of completion as well.⁷

Some of the scientific literature looks at advance care planning in the office setting, primarily with physicians. But other health professionals can also play an important role in helping patients and families with advance care planning. For instance, Lawrence found in the nursing home setting, when the intervention was led by a nurse practitioner, more ADs are completed, and disparities between Whites, Blacks, and other minority groups disappeared, as did differences among those with differing educational levels.³⁷ The ongoing interaction between the nurse practitioner and the patients and families was cited as a key determinant of the successful outcomes.

Deamont et al reported on the impact of palliative consultation with African-Americans in a public hospital with cancer. They found that of 173 African American patients with advanced cancer who were hospitalized during 2007, 88 percent had completed a Do Not Resuscitate (DNR) form, and among those who were discharged alive, 90 percent ultimately enrolled in hospice care. Among patients with decisional capacity, 89 percent appointed a DPOAHC. The Palliative Care Consult Team was responsible for all of the hospice enrollments, 84 percent of

the DPOAHC decisions, and 66 percent of the DNR decisions. Cancer patients seen by the Palliative Care Consult Team improved their knowledge of advance care planning and also their health status, their relationship with their doctors, their willingness to make end-of-life decisions, and the likelihood of enrolling in hospice.³⁸

Song et al. developed a nurse-led intervention, “Sharing Patients’ Illness Representations to Increase Trust (SPIRIT)” to enhance communication about end-of-life issues between African Americans with end-stage renal disease and their chosen surrogate decision makers. During a one-hour interview with a trained nurse, patients, and their surrogates, five elements were covered. The intervention was successful in promoting communication between patients and surrogates, and was well-received by participants. (See Table 1.)³⁹

Table 1: Elements and Goals of the SPIRIT Intervention

Element	Activity	Goal
1. Representational assessment	Patient and surrogate describe illness representations along dimensions: timeline, consequences, controllability, spiritual and emotional representations	To achieve a deeper understanding of the patient’s illness experience and the surrogate’s experience of his/her loved one’s illness
2. Identifying and exploring gaps and concerns	Interventionist identifies and explores gaps and concerns which the dyad may have about illness progression, life-sustaining Rx, decision-making	For each member of the dyad to exchange own values and concerns about life-sustaining Rx at end-of-life
3. Creating conditions for conceptual change	Interventionist encourages dyad to share views and ideas about death and dying and EOL care. Interventionist assists patient to identify his/her threshold for unacceptable outcomes of life-sustaining Rx	To better understand how the dyad values treatment outcomes and what their concerns are
4. Introducing replacement information	Interventionist presents end-of-life scenarios and encourages the patient to clarify their goals for their care and to express concerns. Interventionist assists surrogate to examine his/her willingness to take the responsibility to act on those goals and to appreciate surrogate roles	To clarify treatment preferences of the patient in specific circumstances, and the surrogate’s role in the process
5. Summary	Interventionist summarizes the value of the discussion and the need for future discussions, while assessing	To arrange for any follow-up interventions if needed

Element	Activity	Goal
	any additional support patient/surrogate need (for example., consultation with SW at clinic or spiritual advisor)	

Table based on Song et al³⁹

Other interventions have addressed the health literacy aspect of ACP. It is estimated that 48 percent of American adults lack the necessary health literacy to process health information.¹² Using video-enhanced descriptions of end-stage Alzheimer’s disease in urban, suburban and rural areas, Volandes found that the differences between African Americans and Whites in their preferences for life-prolonging care disappear after African Americans have viewed video footage of a White patient with advanced dementia; the patient is dependent, chair-bound, needs to be fed, and is unable to communicate with her daughters. Video-enhanced descriptions of three levels of care (ICU, hospital ward, home with hospice) were employed in the rural study, but rates of preference for comfort care after viewing the video were remarkably similar in all groups.^{40, 41}

Sudore et al developed an advance directive document for the state of California at a 5th grade reading level, with text-enhancing graphics, clarification of values, and expanded treatment preferences. Participants who reviewed the re-designed AD had higher rates of completion of ADs at six months (19 percent vs. 8 percent) than did those who reviewed the standard California AD form. Among African Americans, there was more involvement at almost every step of the way than among Whites, with 58 vs. 50 percent having contemplated completing an AD, 21 vs. 13 percent having discussions with clinicians, and 19 vs. 9 percent documenting their wishes. Whites were more likely to engage in discussions with family and friends, 51 vs. 44 percent.⁴²

In this study, offering patients a literacy and language appropriate AD may have helped reverse the usual pattern of socio-demographic disparities. The author postulates that it is crucial for clinicians to encourage patients to discuss ACP with their family, since this predicted a much higher rate of discussion with providers and ultimately a greater likelihood that the patient’s preferences will be documented in the medical record.^{42, 43} The study also found that the redesigned AD was preferred, regardless of race, ethnicity, or educational level.

The Process of Advance Care Planning

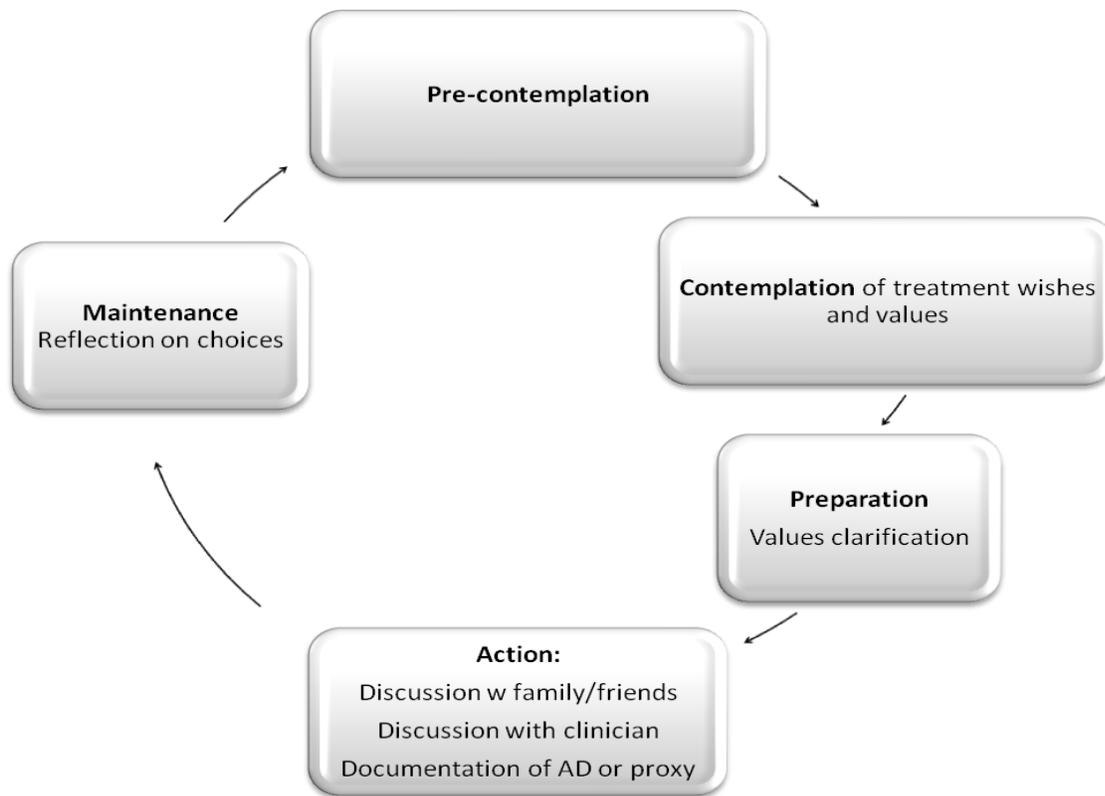
Advance care planning (ACP) is a process, not an event.⁴⁴ It is the *process of planning for future medical care in the event that the patient is unable to make his or her own decisions*. It empowers patients and allows them to have a say in their future care.

Ideally, advance care planning is a process of structured discussion and documentation that is woven into the usual process of care and is reviewed and updated on a regular basis.⁴⁵ It is

designed to ensure that a patient's wishes will be respected in the event he/she is unable to participate in decision making.

Sudore studied the process that patients went through in the six months following their review of two different advance directive documents. The participants, who had no direct healthcare provider intervention after reviewing the document initially, described a process that can be captured with a behavior change model; this includes discrete steps from pre-contemplation, through contemplation (understanding the relevance of advance care planning to themselves and beginning to form the intent to engage in ACP), preparation and values clarification (a transitory phase linking contemplation with action, and with other steps), and an action phase, where discussion takes place with family and friends, and with physicians, and where documentation is completed and given to the physician.⁴³ (See figure 1)

Figure 1: Conceptual model of the process of advance care planning



Based on conceptual model in Sudore et al.⁴³

This process would likely be even more productive and informative if it took place with the aid and guidance of the health care team.

During this process patients explore, discuss, articulate, and document their preferences. The process helps patients identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like—or not like—to receive in various situations. Patients also determine who should make health care decisions on their behalf, should

they become unable to make decisions for themselves. This fosters a sense of control and peace of mind for the patient.

Engaging in advance care planning with patients is important for physicians for many reasons. Patients have a right to participate in the planning of their health care. Physicians have a legal and professional responsibility to respect this, even if the patient loses the capacity to make decisions. The process of determining those treatment preferences builds trust and a sense of teamwork between the patient, the health care proxy, and the physician in several ways. The invitation to discuss future care permits the patient to understand his or her own values, goals, and preferences that govern his or her life. The physician and health care proxy learn about those preferences and needs. The process helps to relieve anxieties and fears on both sides because a spirit of frankness and openness is fostered. Advance care planning is preventive medicine because it avoids future confusion and conflict.

Involvement of others

The physician (or nurse practitioner or physician's assistant) plays an important role in initiating and guiding advance care planning. He or she needs to be involved in some, but not all, stages of advance care planning in order to understand the patient and establish a trustworthy, shared decision-making process. Recent studies suggest that patients prefer discussing these issues with their family members.^{43, 46} But since the physician, nurse practitioner, or physician's assistant will be responsible for the actual medical orders, sufficient involvement is necessary for the provider to feel comfortable that he or she can pursue the patient's priorities for care and goals.⁴⁷

Many providers are concerned that advance care planning is too idealistic or time-intensive to include in their busy practice. However, the patient, proxy, and family can do most of the work if they are given a worksheet and background materials. For provider billing purposes, the time that the provider takes to counsel and provide information about advance care planning can be incorporated into the coding of complexity for the encounter.

The entire health care team—the physician, nurse practitioner, physician's assistant, nurse, social worker, ethicist, and others—can work with the patient, health care proxy, and family to promote advance care planning.⁴⁸ Although the physician and other healthcare providers may make recommendations, the patient makes the final decisions about his/her preferences for care.

Legitimate cultural, ethnic, and age-related differences impact how medical decision-making and advance care planning might be broached with each patient. However, no patient should be denied these opportunities based on generalizations. Rather, the clinician should investigate patient-specific personal or cultural preferences about ACP, and proceed from there. For instance, if the patient has a strong preference against formal documentation of ADs, the clinician should still discuss the patient's wishes, and document that conversation in the medical record. It is important to determine early in the therapeutic relationship how a patient and family want medical information to be shared, and how they want medical decision-making to be handled.

Five Steps for Successful Advance Care Planning

These steps are based on a structured process for discussion from the Agency for Healthcare Research and Quality.²⁰

Step 1: Introduce the Topic

Research shows that most patients believe it is the physician's responsibility to start advance care planning and they will wait for the physician's initiative.⁴⁹ Advance care planning is most easily accomplished when the patient's health is stable, since changes often require a period of adjustment before the patient will have stable goals again.⁵⁰

Ideally, health providers will find that patients referred for cancer care come with documentation of prior advance care planning discussions that have been fostered by the primary care physician. In this case, and if the patient is not actively adjusting to a change in health status, it may be possible to note the presence of an advance directive document and confirm with the patient that the directives they included are still their preferences and do not need to be changed. With that acknowledgement of the topic, it may be possible to recommend that the patient revisit these plans periodically and to suggest a schedule that might be appropriate for this patient. Then, after the therapeutic alliance is well-established, everyone involved is usually comfortable enough to return to the topic as necessary.

However, patients often arrive with no advance care planning documents and without having discussed their options. Health providers must judge when to raise the topic in the context of life-threatening illness or other significant changes in health status. Try to find the best time, considering how patients are adjusting to the new circumstances of illness. If this is not possible, try to ensure that patients have others present on whom they can rely.

Introducing the subject of the AD can be the most difficult part of the advance care planning process. Providers may be reluctant to do so for a number of reasons. Some may be concerned that the subject of advance care planning will frighten the patient or send the wrong message. Therefore, before introducing the topic, patients who are not dying should be clearly told that fact. Emphasize that you have the advance care planning conversation with all patients.

Providers may still be uncertain about the most effective approach to use. In fact, most patients welcome the opportunity to discuss their preferences with their physician, and physicians who routinely engage in the process find it helpful and not too time-consuming. The question is, when and how to raise the topic.

When introducing the topic, start by inquiring how familiar the patient is with advance care planning, even if you have touched on the topic earlier. For patients who already have advance directives, review the documents and amend them if appropriate. An advisory medical directive can be used to amend existing statutory documents. (See step 3.)

Before beginning the process, be prepared to listen to the patient's preferences. Next, explain the goals and the process you recommend using. If you have literature that you would like the patient to read, provide it next, before proceeding further. This is also the time to give them a

validated worksheet (see Appendix 4) to look over, if you have one. Explain the roles of other family members, or a health care proxy. If appropriate, introduce other members of the health care team who will be involved in the process. When possible, identify a health care professional of the same race to speak with the patient and family.

While most patients will welcome the opportunity to discuss these matters, be sensitive to the patient’s comfort level when you introduce the topic. Don’t force the issue if a patient seems uncomfortable talking with you; instead, be supportive and provide information. This can provide time for the patient to adjust to the process. Inform the patient about rules the state will follow in making decisions for patients who are too ill to participate directly themselves if they haven’t designated a health care proxy. Thus, patients who don’t like the default arrangement—even those who find the topic difficult to discuss—should realize they need to make different arrangements for advance care planning. It also allows the physician to feel comfortable using the default process for patients who don’t object, and for patients where advance care planning turns out to be impossible under the circumstances.

When patients want to minimize the decision-making burden for family, suggest they involve family members, friends, and even members of the community in discussions about how to best manage potential burdens. Ask the patient to identify a possible proxy decision maker (who might act on his or her behalf) who can be involved in subsequent conversations. The best proxy decision maker is not always a family member or significant other. Sometimes the decisions are too difficult for people close to the patient, who may be overly influenced by their attachment or by burdens of care. Clinicians should reinforce that the person designated need not be a family member—what matters is they have the patient’s trust, and are willing and able to represent the patient’s wishes.⁵¹ (See Table 2) Encourage the patient to bring that person—or persons—to the next meeting and book a time to follow up.

Table 2: How to Select Your Health Care Agent or Proxy

<i>Name #1</i>	<i>Name #2</i>	<i>Name #3</i>	<i>Criteria for selection</i>
			1. Meets the legal criteria in your state for acting as agent or proxy or representative.
			2. Would be willing to speak on your behalf.
			3. Would be able to act on your wishes and separate his/her own feelings from yours.
			4. Lives close by or could travel to be at your side if needed.
			5. Knows you well and understands what’s important to you.
			6. Is someone you trust with your life.

<i>Name #1</i>	<i>Name #2</i>	<i>Name #3</i>	<i>Criteria for selection</i>
			7. Will talk with you now about sensitive issues and will listen to your wishes.
			8. Will likely be available long into the future.
			9. Would be able to handle conflicting opinions between family members, friends, and medical personnel.
			10. Can be a strong advocate in the face of an unresponsive doctor or institution.

Based on Tool #1 from Consumer’s Tool Kit for Health Care Planning. ABA©2005
<http://www.americanbar.org/content/dam/aba/migrated/aging/toolkit/tool1.authcheckdam.pdf>

Step 2: Engage in Semi-Structured Discussion

Advance care planning succeeds best when you structure discussions with the patient that give them the information they need, and ensure their advance directives reflect their preferences. Allow flexibility in the discussions: Let the patient’s responses help guide the discussion.^{52, 53} (See *Appendix 2: Advance Care Planning Discussion Scripts* for ways to conduct the discussion.) Try to avoid any misunderstanding by reminding the patient that advance care planning is for making decisions only if they should lose their capacity to make decisions, either temporarily or permanently. Emphasize the health care team’s commitment to follow their wishes. Assure them of your intent to protect them from unwanted treatment or under-treatment, and that you can help plan for any caretaking needs of the patient’s family or significant others.

Establish the role of the health care proxy

Involve the potential proxy decision maker in all discussions and planning, so that he/she can have a thorough and explicit understanding of the patient’s wishes. Establish that they are willing and able to carry out this role. Usually, the appropriate role for the proxy during the initial discussions is to listen, perhaps take notes, and ask questions for clarification. A joint meeting between the patient, provider, and health care proxy is important to ensure common understanding, which can be invaluable if the proxy and physician later must collaborate in decision-making.

The health care proxy’s duty is to carry out the patient’s wishes, even if he/she disagrees with the patient. Only if the proxy does not know what the patient would want in a particular circumstance—and is unable to make a judgment based on the patient’s previously expressed wishes, preferences, and values—should the proxy use the best interest standard to make decisions on behalf of the patient.

In all cases, the health care proxy will need to work with the physician and should participate in all decisions that the patient would have been involved in.

Provide patient and health care proxy education

Empowering and preparing both patient and health care proxy is the foundation of advance care planning. This usually requires learning, time for reflection, building trust, speaking with others, and discussions with each other and the health care provider. In order to make informed choices, the patient must understand the meaning of the various clinical scenarios under discussion, as well as the benefits and drawbacks of the various treatment options. The discussion should provide insight into the types of clinical scenarios that might arise, and the types of decisions that proxies most commonly face.

Use words the patient and proxy can understand when defining key medical terms. Explain the benefits and burdens of various treatment options (for example, life support on a ventilator may only need to be used for a short time if the underlying problem is reversible). Remind them that any intervention can be refused or stopped if it is not meeting overall treatment goals. Although the decision to stop a treatment is often more emotionally difficult than the decision to not start a treatment, there is no ethical or legal difference between the two. Because recovery cannot always be predicted, help patients to consider situations involving uncertainty, incomplete recovery, or even death.⁵⁴

Elicit the patient's values and goals

Providers need to develop an understanding of the patient's values and goals related to health and illness. You can facilitate this part of the discussion in various ways. Ask about past experiences, either the patient's own or those of other people the patient knows. Describe possible clinical scenarios, asking what the patient would want in each situation.

Reviewing the range of clinical situations with the patient helps to get a sense of where thresholds exist for withdrawal or withholding of care. Help the patient articulate his or her own general principles, values, and goals for care in given situations and specific treatment wishes. Consider asking the patient if he or she wants to write in a letter how such things should be handled, addressed to the healthcare provider or family.

Some patients and health care proxies may have an emotional response to the material. Empathic listening is a good way to respond to emotional reactions; this allows patients to express themselves emotionally, without interruption, and validates the normality of these reactions.

Use a validated advisory document

To guide the discussion and capture patient preferences, consider using a worksheet or some other well developed and validated tool; for example, a linear or interactive videotape or a software program. (See Appendix 4) Many people find that a worksheet helps manage the discussion so as to help patients identify their values and attitudes regarding health and medical care in general, and also specifically across the range of medical situations, possible goals, and treatment choices they are likely to face. Running through these various scenarios and options

helps to clarify the patient's personal threshold for the use/nonuse of specific interventions. Proxy decision makers can be identified and their roles defined^{55, 56}

Ensure that the worksheet includes the range of potential scenarios your patient should consider. It should bring out the patient's values and goals related to health and medical care in general terms, and also should include the most common life-saving interventions. If a patient already has a life-threatening condition, the conversation may be more focused on specific scenarios and treatment issues.

A number of validated worksheets are available to choose from (see Appendix 4). They are easy to use, provide a consistent approach, and reduce the chance that important information will be left out or framed in a biased way; the preferences they elicit tend to be reliable and durable reflections of the patient's wishes. Once complete, the worksheets can serve as a resource that the patient, health care proxy, and family members can take home and refer to thereafter. They should also be made available to the patient's health care providers, and can also serve as formal advisory documents.

Step 3: Document patient preferences

Formalize the directives

Once the patient comes to some decisions, it is crucial for the health provider to review the advance directive with both the patient and proxy. Check for and help to correct any inconsistencies and misunderstandings. Ensure that the directive provides the information needed to make clinical decisions.

After a final review is complete, ask the patient to confirm his/her wishes by signing the directive. Reassure them that the document can be changed as his/her wishes change, and that desired care will not be withheld simply because of the completion of an advance directive, and—most importantly—that he/she will not be abandoned by care providers. Although any statement of a patient's wishes, written or verbal, can be considered evidence of an individual's intent and should be respected by providers, a formal, written document signed by the patient can help avoid ambiguity.^{34, 57}

Enter the directives into the medical record

Once the directives have been reviewed and accepted, document them in the patient's medical record. When a validated worksheet has been used to structure the planning discussion, the completed, finalized, and signed worksheet can become the relevant entry in the medical record.

In the absence of a validated worksheet or document, the provider may describe the patient's wishes in a written document and ask the patient to review and amend it as appropriate. Once everyone is satisfied, have the patient sign the document, enter it into his/her medical record, and give a copy to the patient and family. It is also useful for the physician and proxy to sign the advance directive, including how to contact them. This should reassure the patient and reinforces the involvement of the physician and proxy in eventual decision-making.⁵⁸

Recommend statutory documents

Patients should be encouraged to complete one statutory document that complies with state statutes, such as the Living Will or Durable Power of Attorney for Health Care. Health care providers should familiarize themselves with the statutory requirements of their state regarding advance directives. Sources for this information include their hospital's legal counsel, their state attorney general's office, the department of health, or their local medical society.

Distribute the directive

It is important that these records remain wherever the patient is receiving care. Place them into a central repository (such as a hospital or a regional or national center). Provide copies to the patient, proxy decision maker, family members, and all health care providers as appropriate. Use wallet cards to help ensure that the information is available when needed.

Change the plan of care

Once preferences have been documented, the provider may need to change the plan of care and put certain procedures in place to ensure that the patient's wishes are followed. When patients wish to remain at home and not be taken to an emergency department or returned to a hospital, appropriate alternative arrangements may be needed. These could include completing a state/locality-approved out-of-hospital DNR order, referral to a home hospice agency, providing appropriate medications, and detailed instructions on how to handle symptoms and crises. Practical suggestions may be helpful. Consider posting telephone numbers by the home telephone to call in an emergency (for example, the hospice nurse on call), or numbers not to call, such as 9-1-1.

Step 4: Review and update the directive

It is important to periodically revisit the subject of advance care planning to review/reaffirm the patient's preferences and to update the documents if and as necessary. Major life events—illness, marriage, the birth of a child, or the death of a loved one—can affect a person's attitude toward their health care and/or end-of-life care.

If a patient decides to change his/her preferences, it is important to make sure the changes are consistent with their desires. Ensure that the physician and surrogate decision-maker fully understand the new wishes.

Changes in preferences should be documented and existing documents should be updated and shared appropriately.

Step 5: Apply the directive to actual circumstances

When patients become incapacitated, the application of prior wishes to real circumstances can be challenging. The following guidelines may help to ensure that a patient's advance directives are followed as closely as possible.

Advance directives go into effect when the patient is no longer able to direct his or her own medical care. Learn to recognize when a patient becomes incapable of making decisions. While situations in which the patient is unresponsive are obvious, if the patient has some ability to respond, the physician must determine the patient’s capacity to make decisions. The capacity to make decisions regarding medical treatment is situation-specific, and involves 4 components:

Does the patient have the ability to:

1. Understand the treatment and the proposed options for care?
2. Appreciate how the information applies to the patient’s situation and its consequences?
3. Reason with the information in a manner supported by the facts and congruent with the patient’s own values?
4. Communicate and express a choice clearly?⁵⁹

(see also EPEC™-O Module 9: Negotiating Goals of Care).

Even though patients may score low on mental status examinations, or have fluctuating periods of lucidity, they may still be able to participate in decisions regarding their care. The capacity to engage in treatment decisions is not a global judgment but is specific to each decision. If the patient’s expressed decisions remain consistent with repetition, this is evidence of the patient’s ability to make decisions regarding care.

Several instruments have been developed to assess a patient’s capacity to engage in treatment decisions, using decision-specific capacity questions. One example is the Aid To Capacity Evaluation (ACE), which recommends sample questions for each of 7 content areas.⁶⁰ (See Table 3)

Table 3: Aid to Capacity Evaluation

Is the patient:
1. Able to understand the medical problem?
2. Able to understand the proposed treatment?
3. Able to understand alternative to proposed treatment (if any)?
4. Able to understand options of refusing proposed treatment (including withholding or withdrawing proposed treatment)?
5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment?
6. Able to appreciate reasonably foreseeable consequences of refusing proposed treatment (including withholding or withdrawing proposed treatment)?

7a. Is the person's decision affected by depression?
7b. Is the person's decision affected by delusion/psychosis?

From Etchells E. et al.⁶⁰

Advance directives should be interpreted in view of the clinical facts of the case. Validated documents are likely to be more useful than short statements or statutory documents. No matter how thorough they are, advance directives cannot anticipate all possible circumstances. An actual, current clinical situation may require the proxy and the physician to extrapolate from the scenarios described in the advance directive, making an educated guess as to what the patient would want if he or she were able to speak for him/herself.

Whenever significant interpretation is necessary, the provider should consult the patient's proxy. Sometimes the provider and/or proxy may believe that a patient would have indeed wanted something other than what is reflected by a strict reading of the advance directive. In this case, try to work together to reach consensus.

Often a pattern of decisions is predictable and follows logically. For instance, patients who decline less-invasive interventions tend to decline more-invasive interventions. Those who accept more-invasive interventions tend to accept less-invasive interventions. If a patient has indicated that he/she would like intervention in a poor-prognosis scenario, it is very likely that patient would also accept intervention in a better-prognosis situation. Likewise, if the patient has indicated he/she would decline intervention in a better-prognosis scenario, it is very likely he/she would also decline if the prognosis were poor.^{61, 62, 63, 64}

Every person has a right to life, and no one should be denied effective medical care unless there is evidence that they intended to decline treatment under some particular circumstances.

When disagreements cannot be resolved, seek help from an ethics consultant or committee. If a provider has moral qualms that conflict with decisions chosen by the patient or the health care proxy, he/she should try to transfer care to another provider who is willing to abide by those choices.

Common Pitfalls of Advance Care Planning

Anticipating and avoiding the common pitfalls is essential to a successful advance care planning process. These include:

Failing to plan: Do not avoid advance care planning. Too often, situations occur and decisions are made without the benefit of advance care planning. Be proactive. It is easy to forget the central role of the patient, and easy to forget the importance of the proxy. Involve both early and often.^{65, 66, 67}

Failing to include the proxy in discussions: Do not leave the proxy decision maker(s) out of the initial discussions with the patient.^{68, 69, 70}

Failing to clarify patient preferences: Vague statements can be dangerously misleading. Be sure to clarify patient preferences if they do not seem clear to you or to the proxy. For instance, patients who make statements such as “I never want to be kept alive on a machine” should be asked to clarify whether their wishes would change if their condition were readily reversible, or if their prognosis were unclear.^{71, 72, 73}

Focusing discussion too narrowly: Avoid isolated do-not-resuscitate (DNR) discussions; they often create chaotic emotions and thoughts in patients who have to imagine imminent death to make the decision. A DNR discussion is usually an indication that other palliative goals and measures should be considered in the context of a range of scenarios.^{74, 75, 76, 77}

Ignoring communicative patients: Sometimes people assume that what a patient indicated for future possible scenarios is what he or she currently wants. Talk to the patient as long as he/she is competent. An impaired patient may still be able to express wishes at some level. In such cases, when the patient’s decisional capacity is not at issue, consider both the advance directive and tangible evidence of the patient’s current wishes. To respect each, they may have to be reconciled.

Failing to read advance directives: Sometimes providers assume they know what an advance directive contains. This is a mistake. Advance directives may apply to aggressive intervention, comfort care, or a wide range of specific views. They must be read and understood on a case by case basis.^{8, 78, 79}

Complementary Application of the Model for Advance Care Planning

Preparation for the last stages of life

The model for advance care planning can be applied to other decision-making processes as patients plan for the end of their lives (for example, planning for bequests, autopsy, burial/cremation, funeral/memorial services, guardianship, choices of caregivers, and settings for care).

Patients also may encounter other issues at the end of their lives. Planning for these is critical if their needs and expectations are to be respected by health care professionals and family members who will survive them. Ideally all patients and families prepare for death well in advance of the final hours of their lives, but in fact most patients with advanced illnesses haven’t prepared for their death, nor have their families. Often, critical discussions have been avoided.

Patients approaching the last hours of their lives have an ultimate chance to finish their business, create final memories, give final gifts, and say their good-byes. You may be able to help them plan around many of these issues.

This kind of intervention requires a refined sense of when the patient and family are ready to engage in this type of planning; this then must be matched to a reasonable sense of the patient's prognosis and an ability to distinguish the needs of the patient and family from the feelings of the professionals. Patients and families are often ready for these discussions before the professionals. Such discussions need not be left for the last possible stages. If conducted when patients have a good amount of time left, they can lead to a helpful sense of peace and order, even as patients get on with living the life left to them and seeking their care goals.

The five-step model for eliciting, documenting, and following advance directives can be used to guide these decision-making processes and document patient choices. These important tasks are generally more than individual physicians can handle, so other members of the interdisciplinary team can help patients and families complete their business and get their affairs in order.

In preparing for death, it is important to understand the perspective and wishes of everyone present: the patient, the family, and the caregivers. Personal expectations, agendas, fears, phobias, and acceptable setting(s) for care need to be clear, since any one person may alter the course of care unexpectedly and may interfere with the patient's wishes that are not clearly known. Personal, cultural, and religious values, beliefs, and practices need to be anticipated and respected— errors made by unknowing caregivers can lead to missed rites or rituals and cause grievous consequences in the eyes of the patient or family members. It is important to acknowledge that some family members have a need to give care and others don't. Identifying these preferences can enable each to participate as closely as his/her comfort will allow.

Advance practical planning

In advance, many patients will choose to get their financial and legal affairs in order, give gifts, and plan for bequests, organ donation, autopsy, burial or cremation, funeral or memorial services, and guardianship of their children as they finish their business. Some patients will even want to give family members permission to build new lives after they die.

Choice of caregivers

As a patient's vulnerability increases, the choice of caregivers for each can be crucial. Early in an illness there is time to discuss and plan for the best configuration. Patients may or may not want family members to care for them. Family members may or may not be able to assume responsibilities for caring. Ideally they should have the opportunity to be family first, and then act as caregivers only if both they and the patient agree to that role. All caregivers need to have the opportunity to change their role if they feel the stress is too great, or if it is compromising their opportunity to finish their personal business with the patient. African Americans have traditionally "taken care of their own." When circumstances preclude them from doing so, and/or they choose to accept resources offered by other caregivers, try to reinforce the idea that they will have a significant and key role in the decision-making process for their loved one, while providing the care that is possible. Emphasize that healthcare providers do not replace family members.

Choice of setting

Try to make the choice of the care setting for the last hours of a person's life as acceptable as possible to the patient, the family, and all caregivers. Each setting will probably include benefits and burdens. Whatever the choice, the setting should permit family members to remain with the patient as much as they wish, giving them opportunities for privacy and intimacy. While many patients may wish to die at home, that choice can expose family members to undue burdens and could compromise their careers, their personal economic resources, or their health. Caring for a dying patient at home may not be the best choice when the number of able caregivers and personal resources are limited, or when family members are afraid of ghosts and would not be able to live on in their home after the death of the patient. There are alternative inpatient settings—a hospice or palliative care facility, a skilled nursing facility, or even an acute care facility—that may lead to a far better outcome.

Summary

Advance care planning should be a routine part of standard medical care, integrated into clinical encounters by the physician and other members of the health care team. Formally, it can be thought of as a stepwise approach including: the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the directives, and application of the patient's wishes when needed. Less formally, the process fosters personal resolution for the patient, preparedness for the health care proxy, and effective teamwork for the professionals.

The process also has pitfalls to be avoided. Vague or misleading statements of wishes can be hazardous; failure to involve the health care proxy risks discord around decisions; premature activation of the directive when the patient is still competent fails to honor the patient's real-time autonomy; and assumptions that advance directives lean toward non-intervention may be inaccurate.

African Americans are generally favorable toward both the concept of advance care planning, and also an individualized, culturally sensitive process of planning. Essential pieces of this process emphasize the patient discussing wishes with family and identifying the person who should be most involved in the decision-making process. This approach can ease anxiety, improve relationships with the healthcare team, and lessen the burden of surrogate decision-making.

African Americans have been keenly aware of historical health inequalities even before research documented the glaring reality of health care disparities. Because of these injustices experienced throughout African American life, health care providers must be willing to understand that the expectation of many African Americans is that they will not receive equal treatment.⁸⁰

“Unless providers are willing to walk in the psychological shoes of African American families, the opportunity to establish trusting relationships will remain a challenge unfulfilled. A verbal validation of the patient's/family's history and current circumstances along with a genuine

willingness to openly discuss a real plan that addresses barriers to care are essential to building trust.” Faye Burrs.⁸⁰

Key Take Home Points

1. Each person has a personal sense of how he/she would like to live and die that is based on personal, cultural, and religious values, beliefs, and preferences.
2. Each person has the right to participate in the planning of his/her health care.
3. Advance care planning is a process to help a patient plan for the potential loss of capacity to make decisions about his/her medical care, either temporarily or permanently.
4. Most patients, including African Americans and other racially and ethnically diverse populations, welcome the opportunity to discuss their preferences with their healthcare provider.
5. The majority of African Americans favor advance care planning.
6. Use a combination of informational and interactive interventions over a period of time to get patients more engaged in advance care planning.
7. Use a structured approach to communicate about advance care planning with patients and families.
8. Engage members of the interdisciplinary team and, when possible, members of the patient’s ethnic group (based on the patient’s self-identification), to help the patient and family engage in the advance care planning process.
9. Use validated, linguistically and culturally appropriate planning documents and advance directive forms.
10. Become familiar with your state laws governing advance directives.
11. Encourage the patient to discuss advance care planning and end of life wishes with family and friends.
12. Encourage patients to designate, formally (when possible) or informally, a surrogate decision-maker who will be empowered to represent the patient’s treatment wishes when the patient is unable to do so.
13. Involve the potential health care proxy in the discussions and planning so that he/she gains a thorough and explicit understanding of the patient’s wishes.
14. Develop an understanding of the patient’s values and goals related to health and illness.
15. Certain patients may choose not to execute formal advance directives. Be sensitive to their actual stated preferences, while carefully documenting discussions with patients and families.
16. Place patient advance directives and any related orders in the medical record at all likely sites of care, and ensure that relevant health care providers know about them.
17. Revisit the subject of advance care planning on a periodic basis, particularly when major life or health changes occur.
18. Apply advance directives in the appropriate circumstances (that is, serious, life-threatening illness, when the patient is no longer able to direct his or her own medical care).
19. The model for eliciting, documenting, and following advance directives can be used to document patient choices and to guide other decision-making processes, such as gift giving and planning for care at the end of life.

Pearls

1. Engaging in an interactive, culturally sensitive process of advance care planning with patients and their families can improve the provider/patient relationship, treatment outcomes, and quality of life for patients and families, as well as the grieving process after death.
2. Ask health care proxies if they are able and willing to fulfill the role. Explain what this means.
3. Identify a patient's personal threshold for life-sustaining intervention.
4. Have validated, culturally and linguistically appropriate worksheets on hand, such as Five Wishes, for use by patients.

Pitfalls

1. Failing to bring up the subject of advance care planning with the patient.
2. Not incorporating advance care planning into routine health encounters with patients.
3. Not involving proxy decision-makers in advance planning discussions with the patient.
4. Not documenting patient preferences.
5. Assuming the content of an advance directive without reading it.
6. Doing something (like procedures and treatments) to the patient that he or she does not want.
7. Omitting the proxy when advance care planning discussions take place between the healthcare provider and the patient.
8. Excluding compromised patients who retain decision-making capacity from making decisions.
9. Allowing healthcare providers' own values and choices to interfere with the patient's expressed preferences.

Appendix 1: Advance Care Planning: The Law and Policy

Common law, federal and state legislation, and official policies of medical organizations support advance care planning.

- **US Supreme Court, 1990:** Upheld the patient's right to self-determination, establishing that the right applies even to patients who are no longer able to direct their own health care, and that decisions for incompetent patients should be based on their previously stated wishes.
- **Federal law, 1991:** The Patient Self-determination Act requires that patients be informed of their rights to accept or refuse medical treatment and to specify in advance the care they would like to receive should they become incapacitated.
- **State law:** The patient's right to specify wishes in advance has been codified into statute in all 50 states. Statutory documents recognized by law include the Living Will and the Durable Power of Attorney for Health Care.

- **Statutory documents** are those that are specifically described and defined in state statutes. These documents help protect physicians who honor a patient’s wishes. When such documents are used, rights, obligations, and protections are clearly defined. Non-statutory documents or advisory documents are also legal, based on common law rights. They are intended to accurately reflect a patient’s wishes. In some states or settings, an advisory document is enough; in others, a statutory form should be used as well. Especially in states where a legal guardian may be necessary if there is no statutory Power of Attorney for Health Care, a statutory form is recommended.
- **Professional policy: The AMA’s Council on Ethical and Judicial Affairs** identified advance care planning as an essential component of standard medical care in 1997 (updated 2010). It called for physicians to conduct proactive advance care planning discussions on a routine basis using advisory documents as an adjunct to statutory documents, such as the Living Will and the Durable Power of Attorney for Health Care. The American College of Physicians’ *Ethics Manual*, 6th edition, 2012, also supports advance care planning.
- **Professional policy: The American Nurses Association Position Statement on Providing Expert Care and Counseling at the End-of-Life (revised 2010)** articulates the roles and responsibilities of registered nurses providing end-of-life care and guidance to patients and families concerning treatment preferences and end-of-life decision-making. It is meant to provide information to guide the nurse trying to provide vigilant advocacy for patients throughout their lifespan as they consider end-of-life choices, and includes discussion of personal and ethical dilemmas that can occur when caring for the dying.

Appendix 2: Advance Care Planning Discussion Scripts

Mrs. Jones has come in for a routine examination:

“Mrs. Jones, I’d like to talk with you about something I try to discuss with all of my patients. It’s called advance care planning. In fact, I feel that this is such an important topic that I have done this myself, with my own physician. Are you familiar with advance care planning? Have you heard the term Living Will? Durable Power of Attorney for Health Care (health care proxy, health care agent, surrogate decision-maker)?”

“Have you thought about the type of medical care you would like to have if you ever became too sick to speak for yourself? Who would you want to make medical decisions for you if you were unable to do so? What type of medical care would you want or not want should you become too sick to speak for yourself? That is the purpose of advance care planning, to make sure that your wishes are heard, respected, and honored, and to ensure that you are cared for the way you would want to be, even in times when you are unable to express your preferences and speaking for yourself may be impossible.”

“Let me assure you that there is no change in your health that we have not already discussed. I am bringing this up now because it is prudent for everyone, no matter what their age or state of health, to plan their healthcare future.”

“Advance care planning will help both of us to understand your values and goals for health care if you were to become critically ill and couldn’t tell us what you want or don’t want. Eventually, if you choose, we may put your choices into a written document that I would make part of your patient record. This document is an advance directive, and it would only be used if you were to lose the ability to make decisions on your own, either temporarily or permanently....”

“Would you like to talk further about the kind of care you would want to have if you were no longer able to express your own wishes?”

“I also like to ask my patients if they would like to identify someone they trust to act on their behalf in the event that they are unable to express their own wishes. This person could be a relative or a friend. Is there someone whom you would want to be part of our discussion, a person you might want to have act on your behalf?...”

“Here is a copy of the form that I would like to use to discuss these things with you at our next appointment. We can talk about it in more depth the next time we meet. Please think about it, talk with your family, and write down any questions you have. Also, next time please bring anyone you would want to include in our discussion....”

Next visit:

Ask questions about specific scenarios. Start by asking if the patient has any questions about the documents given to her on the previous visit. Then proceed to ask about a persistent vegetative state.

“Mrs. Jones, before I talk with you about the document that I gave you at our previous visit, are there any questions you have at this time? I suggest we start by considering a few examples as a way of getting to know your thinking and feelings. I will use several examples for you to consider. Let’s try to imagine several circumstances. First, imagine you were in a coma with no awareness. Assume there was a slight chance that you might wake up and be yourself again, but it was not likely. Some people would want us to withdraw treatment and let them go, others would want us to attempt everything possible, and yet others would want us to try to restore health, but stop treatment and allow the dying process to take its course if it were not working. What do you think you would want under these circumstances?”

Then ask Mrs. Jones similar questions about three other scenarios:

- Onset of coma from which there is a chance of recovery, but with significant disability.
- Onset of dementia when there is already an advanced life-threatening illness.
- If she is already experiencing a significant illness, ask Mrs. Jones questions specific to her current illness:

“We should also consider the situations that your particular illness can cause; that way you can be confident we will do what you want. For sure, all people are different and you may never face these circumstances. Nevertheless, let’s imagine...”

“People sometimes think about circumstances they have seen or heard about. Some may seem worse than death. Do you ever think about such circumstances?”

Finally, ask Mrs. Jones about how she would like to handle a sudden, critical life-threatening illness.

At the end of these scenarios, recap what you understand:

“Well, we’ve gone through several scenarios now. It seems to me that you feel particularly strongly about.... Indeed, you move from wanting intervention to wanting to be allowed to die in peace at the point when.... Do I speak for you correctly if I say that you’ve made the personal choice for deciding to let nature take its course, or placing it in the hands of God, when you are in this condition...? (Describe where in the course of illness the patient has indicated to allow death to occur naturally.)

Conclude by inquiring about broader values and beliefs:

“I think you have given a good picture of particular decisions you would want. Can you also say something about the values or beliefs that you hold? Understanding your more general views can be an important part of getting specific decisions right.”

Next visit:

“Mrs. Jones, have you and [your health care proxy/family member] had a chance to continue the discussion we started two weeks ago? I see you have a completed statement now. Let’s review your choices and preferences.”

“I am glad we went through this planning process together. I have a much better idea of what matters to you than I did before, and that will help me to be a good healthcare provider for you—in general, as well as in case of serious illness.”

“If you feel ready, we can write down your preferences, and all three of us can sign this document and make it official. Then we will put it into your medical record and give you copies to take home.”

After a change in health status (such as relapse), after allowing time to adjust to the new reality:

“Mrs. Jones, we have had some changes in your health since we completed your advance care plans. People sometimes change their wishes, so let’s review the wishes you wrote down before.”

If the patient seems unsure of decisions:

“Your choices have changed on a couple of your earlier decisions when we reviewed your statement. You have also said that you want [name] to be your health care proxy. Would you prefer to give these few decisions over to him/her to decide according to what he/she thinks would be in your best interests?”

“For the remaining decisions that you are clear and firm about, would you like [health care proxy/family member] to stick closely to them, or would you prefer to give him/her room to make changes if he/she thinks that is what you would want?”

Appendix 3: Advance care planning exercise

This is an exercise to help health care providers learn about advance care planning. It is written essentially as a script for a facilitated group process. The educational method is interactive rather than didactic. The scenarios are designed for people in generally good health and would not be duplicated exactly for cancer patients. Rather, this exercise allows health care professionals to get used to advance care planning for themselves as a step in the process of becoming competent in assisting patients in the process.

It is helpful to be able to say to patients and families that you have done your own advance care planning as a matter of routine care. It is also helpful to try to imagine being in a state of serious illness and mental incapacity.

First scenario

We will start by considering a scenario in which you have an advanced illness with a very poor prognosis (less than 3 months if the disease follows its usual course). You are in the hospital in a coma with a poor likelihood of recovery when you develop a small bowel obstruction.

First, consider what you would want to be the *goals* of your care in this circumstance. Would you want: (a) all possible intervention to prolong life, (b) full intervention with all available therapies, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want major surgery? [*Pause briefly.*] How about an intermediate option with a nasogastric tube, and no intake by mouth? [*Pause briefly.*] How about only intravenous antibiotics? [*Pause briefly.*] What about only comfort measures with analgesics and sedatives?

Let's look at what goals you selected. How many of you selected all possible interventions to prolong life? [*You may want to list this on the left-hand side of a flipchart or overhead projector. Count hands and record the number.*] How many selected full interventions, but with early reassessment? [*Count hands and record the number.*] How many chose interventions that might help but are not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many wanted major surgery? [*Count hands and record the number on the right-hand side of the flipchart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with an NG tube? [*Count hands and record the number.*] How many wanted antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice how many of you declined all interventions and wanted only comfort measures. Some of you wanted some noninvasive or minimally invasive measures. Also, notice the inconsistencies. When faced with specific choices, some of you changed to a different "level" as related to overall goals. If we were to move to a scenario of rosier prognosis, we would still be likely to find a range of choices within the group. Many of you would change your choices.

This process provides an opportunity to think about your own internal inconsistencies, how you might value various options, and how you would set limits. Further, it helps you to be specific about your relationship to death and dying.

Many of the questions in your mind are questions patients will have. Many are those that only people with advanced education ask. In fact, lawyers and physicians tend to be either the fastest or the slowest to complete these types of exercises. Most people, regardless of educational experience, find these exercises doable and helpful.

Second scenario

Now, consider a scenario in which you have a mild chronic condition. It affects your day-to-day living to a modest degree. You now contract a life-threatening but potentially reversible condition such as *Staphylococcus aureus* pneumonia. You are barely conscious and cannot make decisions for yourself. Let's go through the same exercise. First, let's discuss goals. Would you want: (a) all possible intervention to prolong life, (b) intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want care in an intensive care unit, including pressors and intubation? [*Pause briefly.*] Would you want a more intermediate intervention, such as multiple intravenous antibiotics and low-dose pressors but no transfer to an intensive care unit and no intubation? [*Pause briefly.*]

Now consider a barely invasive intervention. Would you want IV antibiotics but a limit on the degree of laboratory testing? [*Pause briefly.*] Would you want only comfort care with analgesics and sedatives? [*Pause briefly.*]

Let's look at what treatment options you selected. How many chose all measures to prolong life? [*Count hands and record the number on the right-hand side of the flipchart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with IV antibiotics, but no ICU care? [*Count hands and record the number.*] How many wanted only IV antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice the changes. Most of you wanted interventions that were much more “aggressive.” Contrast your answers to this second scenario with those you gave in the first. Do you have a sense of where your threshold for intervention lies relative to prognosis and disability? Some of you could now move to other scenarios and treatments that would more clearly define your personal threshold for intervention. For many people, it is enough to define where the threshold is, without resolving detailed decisions at the threshold. This is often where physician recommendation plays a stronger role, and proxy discretion comes in. Many patients are content with this.

Notice how most of you selected intervention choices that were consistent with your general goal. This is usually the case. However, some of you chose treatments that didn’t quite correspond with the overall goal. Research shows that trying to predict intervention choices from stated general goals (such as those in a Living Will) is not as accurate as extrapolating from specific preferences. While identifying goals provides a reality check and organizes thinking, it is not a substitute for considering specific examples.

Most people, after weighing other scenarios and having fully completed an advance care planning worksheet, will feel that their views are well articulated. Some proportion of patients, however, will feel that there is something more that needs to be said. Invite them to give you a statement in their own words, such as in a letter. Ask them to consider other matters, such as whether they want to die at home, or whether they want to be autopsied, /or to donate their organs. Help them to understand how best to select a health care proxy. Invite them to choose a health care proxy and to check with the person they have chosen to see if he/she is willing to be formally designated as their health care proxy. If more than one proxy is desired, explain to the patient the potential value of establishing an order of authority should they disagree.

Appendix 4: Validated advisory documents

Aging With Dignity. Five Wishes® directive for advanced care.© Available at:
www.agingwithdignity.org/5wishes.html Accessed 6/5/12

Easy to Use California Advance Health Care Directive
[http://www.iha4health.org/\(X\(1\)S\(5gncnw450au3la55hwyjma55\)\)/default.aspx?MenuItemID=266&&AspxAutoDetectCookieSupport=1](http://www.iha4health.org/(X(1)S(5gncnw450au3la55hwyjma55))/default.aspx?MenuItemID=266&&AspxAutoDetectCookieSupport=1) Accessed 7/10/12

Caring Conversations: Making Your Healthcare Wishes Known
<http://www.cpbmembers.org/documents/Caring-Conversations.pdf> Accessed 7/10/12

Pearlman R, Starks H, Cain K, Cole W, Rosengren D, Patrick D. *Your Life, Your Choices, Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*. Seattle, WA: Patient Decision Support; 1992. http://www.rihlp.org/pubs/Your_life_your_choices.pdf Accessed 6/5/12

Health Professional Resources

National Cancer Institute www.cancer.gov

- Transition Care Planning PDQ
<http://www.cancer.gov/cancertopics/pdq/supportivecare/transitionalcare/healthprofessional/page8> Accessed 7/10/12

Other Resources

Advance Care Planning: Practical Guide for Physicians by Damon K Marquis
https://catalog.ama-assn.org/Catalog/product/product_detail.jsp?productId=OP318800+
Accessed 6/5/12

Aging With Dignity <http://www.agingwithdignity.org/health-care-provider.php> Accessed 6/5/12

Aid to capacity evaluation. <http://crashingpatient.com/wp-content/pdf/ACE.pdf> Accessed 6/5/12

Council on Ethical and Judicial Affairs. Optimal use of orders-not-to-intervene and advance directives. In: *Reports on End-of-Life Care*. Chicago: American Medical Association; 1998:52-58.

Institute on Care at the End of Life. Duke Divinity School <http://divinity.duke.edu/initiatives-centers/iceol> Accessed 6/5/12

- Key Topics on Care at the End of Life <http://divinity.duke.edu/initiatives-centers/iceol/resources/last-miles> Accessed 6/5/12

National Hospice and Palliative Care Organization www.nhpco.org

- African American Outreach Guide. Caring Connections/Duke Institute on Care at the End of Life. National Hospice and Palliative Care Organization.
http://www.caringinfo.org/files/public/outreach/African_American_Outreach_Guide.pdf
Accessed 6/5/12

Physician Orders for Life Sustaining Treatment Paradigm Programs <http://www.ohsu.edu/polst/>
Accessed 6/5/12

Teno JM, Lynn J. Putting advance-care planning into action. *J Clin Ethics*. 1996;7:205-214.

Wharton RH, Levine K, Buka S, Sheinberg N, Emanuel LL. Advance care planning for children: A survey of parental attitudes. *Pediatrics*. 1996;97:682-687.

Patient and Family Resources

National Cancer Institute (NCI)

- Website: www.cancer.gov
- Phone: 1-800-4-CANCER (1-800-422-6237)
- Useful Resources:
 - Advance Directives Fact Sheet
<http://www.cancer.gov/cancertopics/factsheet/Support/advance-directives>

- Accessed 6/5/12
- Coping With Advanced Cancer
<http://www.cancer.gov/cancertopics/coping/advancedcancer/page6>
- Accessed 6/5/12
- When Someone You Love Has Advanced Cancer: Support for Caregivers
<http://www.cancer.gov/cancertopics/coping/when-someone-you-love-has-advanced-cancer/page6> Accessed 6/5/12
- How To Find Resources in Your Own Community If You Have Cancer
<http://www.cancer.gov/cancertopics/factsheet/Support/resources> Accessed 6/5/12

Other Resources:

AARP:

- Advance Directives: Your Critical Action Plans
http://assets.aarp.org/external_sites/caregiving/end/advance_directives.html Accessed 6/5/12

Aging with Dignity

- Five Wishes: <http://www.agingwithdignity.org/five-wishes.php> Accessed 6/5/12

American Bar Association's Commission on Law & Aging

- Consumer's Tool Kit for Health Care Advance Planning, 2nd ed.
http://apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf Accessed 6/5/12

American Cancer Society:

- Find support and treatment.
<http://www.cancer.org/Treatment/FindingandPayingforTreatment/ManagingInsuranceIssues/HealthInsuranceandFinancialAssistancefortheCancerPatient/health-insurance-and-financial-assistance-toc> Accessed 6/5/12
- Health Insurance and Financial Assistance for the Cancer Patient
<http://www.cancer.org/acs/groups/cid/documents/webcontent/002562-pdf.pdf> Accessed 6/5/12

American Society of Clinical Oncology:

- Managing the Costs of Cancer Care
<http://www.cancer.net/patient/All+About+Cancer/Managing+the+Cost+of+Cancer+Care> Accessed 6/5/12

California Advance Health Care Directive:

- [http://www.iha4health.org/\(X\(1\)S\(5gncnw450au3la55hwyjma55\)\)/default.aspx?MenuItemID=266&&AspxAutoDetectCookieSupport=1](http://www.iha4health.org/(X(1)S(5gncnw450au3la55hwyjma55))/default.aspx?MenuItemID=266&&AspxAutoDetectCookieSupport=1) Accessed 6/5/12

CANCERcare:

- Financial Assistance <http://www.cancercare.org/financial> Accessed 6/5/12

- After Treatment Ends: Tools for the Cancer Survivor
http://media.cancercare.org/publications/original/25-ccc_survivor.pdf Accessed 6/5/12

Center for Practical Bioethics:

- Caring Conversations: Making Your Healthcare Wishes Known
<http://www.cpbmembers.org/documents/Caring-Conversations.pdf> Accessed 6/6/12

FamilyDoctor.org:

- Advance Directives and Do Not Resuscitate Orders
<http://familydoctor.org/online/famdocen/home/pat-advocacy/endoflife/003.html>
Accessed 6/5/12

Intercultural Cancer Council (ICC):

- Cancer Facts: African Americans and Cancer
<http://iccnetwork.org/cancerfacts/AfrAmFactSheetRevJune2011Post.pdf> Accessed 6/6/12

Livestrong:

- Practical effects of cancer: <http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Practical-Effects-of-Cancer> Accessed 6/5/12
- Assessing and managing your financial situation. <http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Practical-Effects-of-Cancer/Assessing-and-Managing-Your-Financial-Situation> Accessed 6/5/12

National Hospice and Palliative Care Organization (NHPCO)

- Website: www.nhpco.org
- Phone: 1-800-658-8898
- Useful Resources:
 - Planning Ahead: Have you made a plan? (Information about Advance Directives, including State specific Advance Directives)
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289> Accessed 6/5/12
 - <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3277> Accessed 6/5/12

TMTM On Our Own Terms: Moyers on Dying

- Discussion Guide
<http://www.pbs.org/wnet/onourown/terms/community/pdf/discussionguide.pdf> Accessed 6/5/12

U.S. Living Will Registry

- <http://www.uslivingwillregistry.com/default.asp> Accessed 6/5/12

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³ EndLink Resource for End of Life Care Education. Module 1. Advance Care Planning. Robert H Lurie Comprehensive Cancer Center of Northwestern University. http://endoflife.northwestern.edu/eolc_advance_care_planning.cfm . Accessed 6/5/12.

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Self-Assessment Questions

Module 13 AA: Advance Care Planning

1. Mr. Joseph is a 69 y.o. African American retired business owner with advanced prostate cancer, who lives alone independently. His daughter has been trying to engage him in discussions about what his wishes are for end-of-life care, but he keeps changing the subject and deflects her concerns. He is likely exhibiting:
 - a). shared decision-making
 - b). deferred autonomy
 - c). implied surrogacy
 - d). lack of capacity

2. Mr. Robinson is a 34-year-old pipe fitter who has been admitted with hepatoma and liver failure secondary to hepatitis and alcohol use. He lacks capacity to make decisions for himself. He has not indicated any prior wishes or completed any advance directive form. The physician is best guided by:
 - a). duty to prolong life at all cost
 - b). medical judgment about what is best
 - c). state law governing substituted judgment
 - d). the family's wishes even though the physician suspects selfish motives

3. Ms. Monadnock is an 63-year-old African American former waitress who has recently been diagnosed with breast cancer. She is about to undergo definitive therapy for localized cancer. You inquire whether she has completed any advance directives for health care. She answers no, adding that no one had ever mentioned it to her before. To increase the likelihood that she will complete and advance directive, you should:

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- a). give her a brochure about advance care planning, and wait for her to return completed AD forms
 - b). give her a linguistically and culturally appropriate state-approved advance directive form for her to complete during her current visit
 - c). verbally explain the process of advance care planning and request that she bring completed AD forms at her next visit
 - d). verbally explain the process of advance care planning, give her a validated planning document, and encourage her to go through it with her family
4. Mr. Arteresian is an 84-year-old retired judge recently discharged from the hospital for evaluation of rectal bleeding. A malignant polyp was removed. A definitive resection is planned. He completed a Living Will and named his son as his Power of Attorney for property and health affairs. In the office, he says he would also like to make plans about his funeral and wants to arrange for his body to go to the medical school. Your best response is to:
- a). tell him to talk to his son
 - b). note this in the medical record
 - c). advise him to contact the medical school about how to do this
 - d). all of the above

Self-Assessment Answers

Question 1. The correct answer is: b)

Although African American elders may exhibit autonomy in their day to day living, they often prefer a style of “deferred autonomy” whereby they postpone involvement in future care decision-making.

Question 2. The correct answer is: c)

This question is aimed at the issue of substituted judgment in the absence of written advance directives. Laws governing who makes decisions for the patient in the absence of clear evidence about what the patient wanted vary from state to state. Many, but not all, recognize “next of kin” in the absence of written directives. Although medical judgment is important, it is advisory to the person who has the authority to speak for the patient. This is determined by state law. The family is not always the best decision maker.

Question 3. The correct answer is: d)

Informative interventions alone without interactive interventions have not been found to increase the rate of advance care planning. Patients require time to process important topics like advance care planning, and it would not be appropriate to ask Ms. Monadnock to complete the forms at a single visit without ongoing discussion. Although using linguistically and culturally appropriate AD’s is important, the most important step in the advance care planning process appears to be patient discussion with family and friends, as this is predictive of much higher rate of discussion with providers and ultimate documentation in the record of patient’s preferences.

Question 4. The correct answer is: d)

This question is aimed at the larger sphere of advance planning that is appropriate for patients with advanced disease. The patient’s son, as Power of Attorney for property, will be responsible for his father’s affairs after death, including disposition of his body. It is useful to put all this information in the medical record, both to help ensure that the son acts in accordance with the patient’s wishes and to ensure continuity and communication. Arranging the details ahead of time will expedite the process after death has occurred.