



## Palliative Care Improves Quality of Life for Seriously Ill

### *Palliative Care vs Hospice Care.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Palliative care focuses on improving a patient's quality of life by treating symptoms caused by his/her disease or by life-prolonging treatments he/she is receiving.

**Palliative Care:** Palliative care is the care provided to patients that focuses on treating the burden caused by an illness or the burden caused by the treatment of the illness, rather than treating the disease itself. Unlike an oncologist who provides cancer treatments, someone providing palliative care would treat the symptoms caused by the cancer and/or the symptoms caused by the cancer treatment. Palliative care tries to promote quality of life by adding a focus on social and psychosocial issues raised by the disease and by dealing with some of the ethical and spiritual issues associated with serious illness, in addition to medical issues. In the U.S., we have palliative care specialists who work with primary care providers to help provide palliative care to patients with severe illnesses. Basically, every doctor or nurse should be able to provide *primary* palliative care as part of his/her job as a health care provider. Palliative care specialists deal largely with serious illnesses -- illnesses that may progress and potentially lead to either severe dysfunction or death. **Hospice Care:** In the U.S., hospice care is care that is largely a funded benefit through Medicare for people who have <6 months to live. Therefore, hospice care and palliative care are very different. For example, a patient can receive palliative care at the same time they are undergoing chemotherapy or other life-prolonging therapies. Hospice care focuses solely on quality of life as a patient nears death, so generally, life-prolonging treatment is not provided at the same time. As an insurance benefit, hospice care allows doctors, nurses, social workers, and chaplains to provide care in the patient's home, focusing on improving the quality of the patient's life as they approach death. (Reviewer-).

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## Trends Show U.S. Doing Better Job of Building Palliative Care Programs

*Palliative Care Services: Program Development and National Trends.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

In the U.S., most large hospitals have specialized palliative care consult services, while smaller hospitals may or may not offer similar programs. These services are needed to improve care for seriously ill patients.

In this special presentation, Dr Robert Arnold describes the development of palliative care programs, especially at his institution (the University of Pittsburgh Medical Center [UPMC]). **Palliative Care Programs:** Originally at UPMC, we had no palliative care specialists. However, in 2001, the Open Society Institute, which is George Soros's philanthropic society, funded me to be a "Project on Death in America" clinical scholar. As part of that opportunity, we developed a palliative care consult service at 2 of UPMC's hospitals. In the U.S., most palliative care programs initially focused on in-hospital subspecialty consult services. Clearly, however, before there were official palliative care programs, palliative care was being provided through oncologists, HIV doctors, general internists, and family medicine doctors as part of their health care work. So in 2001, UPMC had its first *specialty* consult service, which involved a doctor and a nurse practitioner. Eventually our program grew to include social workers. Then a similar program was developed by other individuals at one of UPMC's cancer hospitals. Since then, we have developed multidisciplinary consult services at all UPMC hospitals, and the goal of these services is to add another layer of specialized support to what once was provided only by primary care doctors or other specialists. **How It Works:** At UPMC, our Palliative and Supportive Institute is largely a consult service. Therefore, people contact us and ask for our help in seeing their patients to help address ongoing issues or to meet current needs. **National Trends:** Almost all large hospitals like UPMC have palliative care consult services, while smaller hospitals may or may not offer similar specialized services. I believe health care systems are realizing that, to do a good job of taking care of seriously ill patients, they really need to develop palliative care programs. As such, I see a national trend to do a better job of developing palliative care programs. (Reviewer-).

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## It's Win-Win -- Palliative Care Saves Money, Improves Care

### *Palliative Care Services: General Overview & Fellowship Training.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Available data show that palliative care services reduce health care costs and improve the care that patients receive. To specialize in palliative care, additional training is available via highly structured programs.

In the U.S., hospice care is an insurance benefit provided to patients who have <6 months to live. However, unlike hospice care, palliative care is beneficial for patients undergoing life-prolonging treatments. **Palliative Care Advantages:** Available data show that palliative care services save money from the hospital's perspective. Additional data demonstrate that palliative care services improve the care that patients receive because they have fewer symptoms and do better overall. **Services Overview:** At our institution, palliative care services are generally delivered as a consult service. For example, a patient has severe pain or nausea/vomiting. The primary care team would consult us, and our job would be to help treat the patient's pain in an effort to reduce his/her symptoms and improve quality of life. In other cases, the patient and/or family is facing a very difficult choice about whether to proceed with a course of treatment. Palliative care services may be consulted by the primary team because the patient and/or family needs someone to sit down with them, discuss their values, and talk about what's most important to them. These can be very difficult conversations. **Specialized Training:** To be a doctor specializing in palliative care, year-long fellowships are available. These programs are highly structured. Therefore, doctors specializing in palliative care undergo a relatively long training in this area and are very advanced at completion of the fellowship, similar to those completing an oncology fellowship or other specialized fellowship. For nurse practitioners and social workers wanting to specialize in palliative care, our institution (the University of Pittsburgh Medical Center) also offers a training program. **Reconciling Conflicts:** A great deal of palliative care involves communication. For example, a hospitalized patient has very little chance of being discharged. When reviewing the goals of care, a medical student offers the patient/family CPR as an option, but in reality, CPR will not be helpful for the patient. Some family members want to include CPR on the goals of care, while others do not. As a member of the palliative care service, I would approach the situation by asking the family to tell me what other people have told them would help. Then I would ask them to explain what outcome they are hoping for. After listening to them and discussing the situation with them, I would then offer a recommendation. In my experience, most families are relatively realistic. However, in situations like this, people are often also very sad, so I need to deal with their sadness. If you cannot deal with their sadness, it is more difficult for them to decide. (Reviewer-).

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## Conversations About End-of-Life Care Are Difficult but Essential

*End-of-Life Care: Conversations With Family and Advance Directives.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Approximately 30% of people actually have conversations about end-of-life care with their families. Only 20% of Americans have advance directives, but up to 50% of people aged >65 years have advance directives.

Approximately 90% of people consider conversations about end-of-life care to be important, but only 30% actually have these conversations with their loved ones. These conversations can be very difficult, and often people are very sad when they get around to having these conversations. Therefore, to have these conversations with family members, people often need help. Sometimes, people need to be convinced that they *can* have this conversation without causing the other person/people to give up hope. As part of our palliative care consult services at the University of Pittsburgh Medical Center, we assist patients and families with having these end-of-life conversations. In my experience, I find that I must sometimes make them understand that I can help them get through the conversation. Once people have this conversation, they are glad they did it, but it is still a difficult task. **Advance Directives:** Advance directives are legal documents that allow patients to communicate their wishes about end-of-life care to family members, health care providers, etc, before actually needing that care. Data suggest that about 20% of Americans have advance directives, and some studies say that up to 50% of people aged >65 years have advance directives. That statistic seems high to me in my clinical experience, but that is what some data suggest. Advance directives are a little like directions for an automobile trip -- they should give people a sense of where the patient wants to go with his/her end-of-life care rather than what the answer is to each and every situation encountered along the way. Therefore, the patient's goals are more important than the advance directive itself -- it is the fact that the patient has communicated his/her end-of-life wishes to loved ones. Some advance directives are very specific, such as detailing whether CPR should be done. I believe these types of directives are not very helpful. Most people are not in favor of or against specific interventions. Instead, they are really hoping to achieve or not to achieve certain goals. Therefore, I believe what is really important about advance directives is that they allow patients and families to talk about what is important if someone should become seriously ill. (Reviewer-).

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## Patient's End-of-Life Choices Often Based on Family's Desires

*End-of-Life Care: Communicating Patient's Wishes in Difficult Situations.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

It is normal for people to do things for their family that they would not personally do on their own. When making decisions regarding end-of-life care, patients often base their decisions on their family's desires.

As a palliative care specialist, Dr Arnold has encountered several types of special circumstances regarding end-of-life care for patients. **Lack of Advance Directives:** Advance directives are legal documents that allow patients to communicate their wishes about end-of-life care to family members, health care providers, etc, before actually needing that care. In many cases, the patient does not have advance directives. If the family and caregivers are not clear regarding the patient's wishes, then the goal is to determine what their "substituted judgment" would be. In other words, if patients were able to speak for themselves, what would they say? So, my role becomes one of bringing the patient's voice into the room when talking to his/her family. I talk to family about the kind of person the patient was. What did he/she care the most about? What things were most important to him/her? In answering questions like these, we can sometimes determine, to the best of our abilities, what the patient's wishes would be for end-of-life care. **Differences of Opinion:** Sometimes within a family, there are differences about how much or how little care should be provided to a patient. To resolve these conflicts, I first ask whether I can speak with the patient. Then I talk to the family to determine *how* and *why* they disagree. For example, did family members have different conversations with the patient? Did they talk about different things? Were issues raised or addressed differently? How can I try to talk to them in a way that would be helpful to all of them? **One-on-One Conversations:** In my experience, I find that it is sometimes good to talk directly with the patient without the family present. People often say, "He's only doing it for his family." Well, it is normal to do things for your family, and it is ethically acceptable to do things for your family. For example, many people go to their children's play at school, not because they really want to see the play, but because they know it brings joy to their children. In truth, we do many things for our children that we personally would not want to do on our own. Therefore, sometimes, patients will be able to have an end-of-life conversation when alone with me but then cannot have the conversation when their families return. As a clinician, part of what I do is to help patients talk to their families. (Reviewer-).

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## Decisions About End-of-Life Care May Contain Hidden Meanings

*End-of-Life Care: Patient Autonomy.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Decisions about end-of-life care should ideally respect the patient's autonomy. Yet, negotiation and compromise between the patient and family are often required because the patient's values are tied up in his/her family.

As a palliative care specialist, Dr Arnold has encountered several special circumstances regarding the decisions for a patient's end-of-life care. Here, he describes the importance of focusing on what the patient wants and deciphering what the family may actually be saying when they request that all possible life-prolonging measures be taken for the patient. **Patient Autonomy:** At times, the family's wishes for end-of-life care clash with those of the patient. As a clinician, I believe that one of my roles is to help everyone involved determine the true story. In the end, our job is to respect what the patient wants. Yet, "want" is a strange word. For example, I *want* to be on the beach, and I *want* to eat as much as I desire and not gain weight. There are many things that I *want*, some of which may conflict. Determining what the patient *wants* can be difficult. I begin by talking to the family about what is important. It is okay for a patient's family to have different goals or desires than those of the patient, and it is okay for them to try to convince the patient to make a different decision. In the end, the patient needs to figure out how he/she wants to approach end-of-life care. This may require some loving guidance. In a different scenario, family members may say, "Well, my dad said this, but we should do that." In those cases, my job is to help them determine whether it is their emotions talking or whether the choice is actually what their dad would want even though the family member does not want to listen. In those cases, I often say, "We really need to do what your dad would want." In the end, the patient's autonomy should predominate. And yet, in the clinical world, negotiation and compromise are often required because the patient's values are tied up in his/her family. **"Do Everything Possible":** Sometimes, patients or families (or both) ask for everything possible to be done for the patient, when, from the medical perspective, there is really no point in doing so. I approach these situations by asking the family, "Tell me what you mean by 'everything.' Tell me what you're hoping for." Often, when people say they want everything, what they are really saying is, "I don't want my mom to die." It's an emotion statement. They aren't necessarily saying that they want every possible measure to be taken to keep the patient alive. Most families do not have any idea what "everything" is. So, one of my roles is to help people understand what "everything" is and what they are actually trying to say when they ask for "everything." (Reviewer-).

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## Patients' Values Vary Widely, So Listen Carefully

### *End-of-Life Care: Religion & Cultural Considerations.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Being knowledgeable about every religious tradition is probably not as important as having the ability to talk to patients in a straightforward manner, allowing them to explain what is most important to them.

Dr Arnold is a palliative care specialist at the University of Pittsburgh Medical Center. As part of his job, he helps patients have conversations with their families regarding end-of-life care. The patient's religion and/or culture can greatly affect these conversations and other end-of-life decisions. **Vitalists:** 10% of Americans are "vitalists" who believe that life is worth living, even if in a comatose state. My view is that, if the patient is a vitalist, then it is okay for the family to request life-prolonging care. In these cases, we should focus on keeping the patient alive because those are his/her values. However, we should not do things that are not supported by current evidence or are not medically appropriate within standard medical treatment. In general, as health care providers, we should be willing to be respectful of the variation in people's values. **Miracles:** When people tell me, "I'm hoping for a miracle," I reply by saying, "I think that's fabulous." It would be great if a miracle would occur, because a miracle is an unpredictable event. The question isn't whether they hope for a miracle. The question is what else they are hoping for and what can I try to help them achieve, given the medical treatments available to me. For people who say, "It's in God's hands," then it *is* in God's hands. But as a human, I need to make recommendations and suggestions given what I can or cannot do. **Preparing for These Conversations:** Doctors who complete fellowship training to become a palliative care specialist receive some education to prepare them for dealing with patients from different cultures and religions. However, because there are so many religions and cultures and so many individual variations, it is difficult to prepare for them all. I believe that the real thing I need to say is, "Tell me what's important to you as you look toward the future. What are you concerned about when you think about the future? Are there any religious traditions that I need to know about?" Therefore, being knowledgeable about every religious tradition is not as important as my ability to talk to all patients in a straightforward and kind manner, allowing them to tell me about what is most important to them. (Reviewer-).

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## 'Very-Low-Probability Care' May Be Better Term Than 'Futile Care'

*End-of-Life Care: Training for Difficult Conversations and Use of the Term "Futile Care".*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

"Futile care" indicates a treatment that, biologically, is unlikely to achieve the outcomes hoped for. This term may not be appropriate to use in conversations with patients and families regarding end-of-life care.

Dr Arnold is a palliative care specialist. Here, he describes part of his approach in discussing end-of-life care with patients and their families. **Futile Care:** The term "futile care" is often used to describe care that is very unlikely to succeed. In conversations about end-of-life care, I don't typically talk about futile care. I think this approach does not work, and I think all doctors at my institution (the University of Pittsburgh Medical Center [UPMC]) also consider the use of this term a bad idea. The term "futile care" can also indicate care that we consider to be inappropriate because the benefits are outweighed by the harms. So, it is easier for the patient and family if we discuss this (treatment benefits vs harms) rather than just use the term "futile care." In my experience, "futile care" indicates a treatment or procedure that, biologically, will not achieve the outcomes hoped for. Instead of being "futile care," I think it is better termed "very-low-probability care." **Difficult Conversations:** I am willing to have families request end-of-life care options that I would not do for my loved ones because I know that the values I have for my loved ones may differ from the values that others have for their loved ones. I believe that one of the reasons we do a poor job in negotiating end-of-life care is that families do not always understand what it is they are requesting. We need to talk very straightforwardly about care options so that they can understand the potential risks and benefits. We also need to attend to the emotional reactions of families, because when people are really upset, they do not think clearly and, thus, may make poor decisions. **Training:** We can train doctors to have better conversations about these matters. I work with a nonprofit company called VITALtalk, and we spend a lot of our time trying to help clinicians have better conversations about patient care. At UPMC, we have training 3-day experiential courses for specialists (oncologists, critical care doctors, nephrology doctors, cardiology doctors, and palliative care doctors) during which they practice having these conversations. These conversations are not something that we are naturally good at knowing how to do without practice, so the goal of our training sessions is to practice and to help people be better. (Reviewer-).

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Keywords: End-of-Life Care, Training for Conversations About Care, Futile Care

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## Must Balance Medical Ethics With Patient's Cultural, Religious Values

### *End-of-Life Care: Accommodating Cultural Values.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Families sometimes request that a parent not be told about a cancer diagnosis. However, providers must disclose the diagnosis to the patient, but it can be done in a way so that the patient can easily decline talking about it.

As a palliative care specialist, Dr Arnold shares some of his experiences in managing end-of-life care for patients and their families. **Cultural Values vs Medical Ethics:** In these sometimes difficult conversations, the doctor must explore the patient's cultural values and attempt to accommodate those values within the limits of sound medical ethics. For example, the patient may be a Muslim woman who wants to be seen by only female doctors or nurses. Or perhaps an Asian family does not want their mother to be told about her cancer diagnosis. In my experience, the best way to accommodate these different cultural beliefs is to first have a respectful conversation with the patient and/or family members. For example, you may say, "If the patient wants to be seen by a woman only, here is what we can do to accommodate this request." However, if the family requests that a patient not be told about a cancer diagnosis, then our reply should be, "Let's discuss this request. It is okay that *you* (the family) don't want to talk to your mom about the diagnosis, but we (the health care providers) need to disclose the diagnosis to her and hear what she has to say. We can present it to your mom in such a way that she can easily say that she doesn't want to talk about it. We don't want to force your mom to talk about anything she doesn't want to talk about." In my experience, families often request that a patient not be told about a diagnosis because they are worried that the patient will become very sad. So if we can help the families first think through the conversation, it works much better. **Provider's Values:** What about doctors, nurse practitioners, physician assistants, or nurses who do not want to participate in certain conversations or procedures because of *their* culture, religion, or personal beliefs? Our palliative care services team can get involved with accommodating the provider's wishes as well. My view is that we should not force people to have conversations that they don't want to have. Even if a patient says, "I don't want to talk about this. I want you to talk to my children," then, in those cases, I believe we should talk to the children for the patient. (Reviewer-).

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## Physician-Aided Dying Requires Moral Tolerance in Medical Community

*Physician-Aided Dying: A Palliative Care Specialist's Perspective.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

In 2015, California became the fifth U.S. state to legalize physician-aided dying, allowing physicians to prescribe lethal doses of drugs to terminally ill patients who request the physician's help in dying.

As a palliative care specialist, Dr Arnold shares his view on physician-aided dying (doctor-assisted suicide).

**Legalization:** In 2015, California became the fifth U.S. state to legalize physician-aided dying, allowing physicians to prescribe lethal doses of drugs to terminally ill patients who request the physician's help in dying. Four other U.S. states have also legalized physician-aided dying: Washington, Oregon, Vermont, and Montana. Efforts are underway to legalize this practice in New Jersey and Massachusetts. As a palliative care specialist, I believe this is a controversial topic about which reasonable people can disagree. I believe the more fundamental topic that needs addressing is that we need to do a better job of caring for patients who have serious illnesses and who may be dying. All data suggest that we are not doing a good job of caring for these patients. We need to help doctors and nurses do a better job of caring for symptoms experienced by seriously ill patients and supporting their families in an effort to decrease the amount of suffering and burden of caregiving. I personally am not sure if I could be involved in physician-aided dying, and yet I know doctors (whom I respect very much) who believe that physician-aided dying is part of their job. Therefore, I believe that this is one of those issues about which we should have some moral tolerance. However, I am quite concerned about the degree to which inequities that already exist in our country may be magnified through laws about physician-aided dying. Yet, I understand that this is an empirical fact. **Safeguards:** Do you think there are any specific safeguards needed in the states where physician-aided dying is legal or may become legal? I think the safeguards that are available in Oregon and California are reasonable. For example, the patient is required to see >1 doctor before proceeding with their decision. Because I don't practice physician-aided dying, I don't know the safeguards as well as I probably should. Data from Oregon seem to suggest that the law has worked relatively well. It will be interesting to see how it works in California where the population is much more diverse than the population in Oregon. (Reviewer-).

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Keywords: End-of-Life Care, Physician-Aided Dying, Doctor-Assisted Suicide

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## AMA Supports Palliative Care, Not Physician-Aided Dying

*Physician-Aided Dying: AMA Code of Medical Ethics Opinion 2.211.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

According to the American Medical Association's Code of Medical Ethics, Opinion 2.211, physician-aided dying is fundamentally incompatible with the physician's role as a healer.

As of 2015, 5 U.S. states have legalized physician-assisted dying (doctor-assisted suicide). In contrast, the American Medical Association's Code of Medical Ethics, Opinion 2.211, addresses physician-assisted suicide. The following material is quoted directly from Opinion 2.211: *"Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (eg, the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide). It is understandable, though tragic, that some patients in extreme duress -- such as those suffering from a terminal, painful, debilitating illness -- may come to decide that death is preferable to life. However, allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks. Instead of participating in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Multidisciplinary interventions should be sought, including specialty consultation, hospice care, pastoral support, family counseling, and other modalities. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication."* As a palliative care specialist, I agree with the positive statements made in this opinion issued by the AMA. However, I believe there is still a lot of controversy about the other things. I believe that reasonable people can disagree about the physician's job as healer. For example, there are many things that I do as a palliative care doctor that aren't focused on healing. In fact, the surveys that have been done from physicians show a tremendous split among physicians about physician-aided dying. (Reviewer-).

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## Legalizing Euthanasia May Make the Practice Difficult to Limit

### *Physician-Aided Dying: Trends in Belgium and the Netherlands.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

A trend toward more physician-aided deaths is seen for Belgium where the practice is legal. Some medical ethicists see this as a "slippery slope:" legalizing the practice may make it hard to limit and control.

In some European nations, physician-assisted dying (doctor-assisted suicide) has been legal for some time for patients who meet all legal requirements. A package of articles was published in 2015 by *JAMA Internal Medicine* in which European trends in euthanasia and assisted suicide were reviewed. **The Netherlands:** In 2002, the Netherlands had 645 termination-of-life/assisted-suicide requests. Of these requests, 162 were granted (25%), 300 were refused (47%), 124 died before their request could be assessed (19%), and 59 requests were withdrawn (9%). Of 40 requests submitted because the patient was "tired of living," 11 were granted. (Resources: [1] *JAMA Intern Med.* 2015; 175 [October 1]: 1640-1641 and [2] *JAMA Intern Med.* 2015 [October 1]: 1633-1640.) **Belgium:** Euthanasia was legalized in Belgium in 2002. To determine how euthanasia has changed with time in Belgium, a random sample of 6871 deaths from January through June 2013 was compared to a similar sample of deaths in 2007. The number of euthanasia requests was 3.5% in 2007 and was 6.0% in 2013 (a 60% increase). The proportion of requests granted was 54.5% in 2007 and was 76.5% in 2013. The most important reason for granting a request was the patient's reported physical and mental suffering with a lack of prospects for improvement in their condition. (Resource: *JAMA Intern Med.* 2015; 175 [October 1]: 1703-1706.) **Implications:** Both studies depict a trend toward a growing number of physician-aided deaths in these countries. Some medical ethicists refer to the growing rates of legalized physician-aided dying as a "slippery slope," meaning that, once doctors are allowed to assist patients in dying, we may be unable to limit the euthanizing of those who want to die. Others view the practice as consistent with an increased emphasis on patient-centered care. Therefore, in the U.S., we will have to wait and see how this topic plays out in the 5 states in which physician-aided dying has been legalized. (Reviewer-).

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## Health Care Is Human Endeavor, Not Just Caring for a Body

*End-of-Life Issues: Death and Dying.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Health care, with all its technical sophistication, truly remains a very human endeavor. Attempts at humanizing the dying experience remind us that we are dealing with a person, not just a body.

Like numerous hospitals in the U.S., the University of Pittsburgh Medical Center (UPMC) participates in the No One Dies Alone (NODA) program. NODA is a nationwide program developed by nurses. Visitors ("compassionate companions") stay at the bedside of dying patients whose families cannot be present. Because UPMC is a quaternary care hospital, families often cannot arrive in time to be with dying patients. In such cases, compassionate companions stay with the patients so that, when they die, there is someone in the room with them as a witness to their dying. These volunteers can be sitting quietly, they can pray or sing for the patient, or they can read to the patient, depending on the patient's level of awareness. In Canada, the "three wishes" program seeks to humanize deaths in ICU patients. This is similar to nursing home projects in which pictures of the patients are placed in the room, and families are asked about a wish that their loved ones might have had, such as having music in their room. In other words, are there ways to bring the patient into the room to remind them and us that the focus is on an actual person, not just on a body? All this serves to remind patients, providers, and family members that health care, with all its technical sophistication, truly remains a very human endeavor. **Death:** Definitions of life and death are social definitions. In my opinion as a doctor and palliative care specialist, I do not believe there is a biologic truth that "death" represents. Instead, it is a continuum. Nonetheless, I believe that our approach to defining life and death *biologically* seems to be a reasonable definition. However, *philosophically*, there can be arguments about what constitutes life and death, and I believe that death does not have the certainty that we would like to have as biologists. As a matter of *law*, we often develop categories that, biologically, may not be completely accurate. Nonetheless, I don't believe we will develop better definitions of death. While saying, "Bodies can somatically survive even after someone is declared dead via neurologic criteria," may be true, it does not mean we should change the definition of death. (Reviewer-).

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## 'Brain Death' Terminology Not Helpful for Families of Dead Patients

*End-of-Life Issues: Brain Death and Dead on Arrival.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

As a doctor and palliative care specialist, I do not use the term "brain death." Patients are simply dead. I do not believe that families should be allowed to independently define whether someone is alive or dead.

Because defining death may be based on legal, biological, and philosophical criteria, we encounter situations in which families, health care providers, and the legal system may disagree on whether a patient is actually dead. **Brain Death:** In California, a teenage girl bled after a tonsillectomy and was declared to be "brain dead" by the health care providers, but the family insisted on keeping the child alive (or, attached to artificial life support). Because the parents and the hospital were at odds about the girl's status, the child was transferred out of the hospital with a death certificate. The child was transferred to a facility in New Jersey. **Dead on Arrival:** In Texas, a young pregnant woman was found by her husband and taken to the hospital. The woman was declared dead on arrival. However, the hospital thought it had a duty to keep the patient "alive" to protect the fetus, but the husband said, "She wouldn't want that. I don't want that. We don't want that." Because the hospital felt that they might have some obligation to the fetus, they asked the courts to consider the case. The court ruled that, in fact, the woman was not a patient because, when she arrived, she was already dead. So the court ruled that the family's wishes -- the patient's wishes and the husband's wishes -- be respected.

**Accepting Death:** As a doctor and palliative care specialist, I do not use the term "brain death." Patients are simply dead. There are 2 ways of determining whether people are dead: (1) cardiopulmonary criteria -- their heart stops for the required amount of time to be considered dead -- and (2) brain criteria -- the brain and the brainstem are not working using current technologies to evaluate the brain. If someone is dead and meets the legal definition of death, then he/she is dead. I do not believe that we should allow families to independently and individually define whether someone is alive or dead. From a societal point of view, this does not make much sense. In the case of the California girl who was declared dead after a tonsillectomy, I would have helped the family by saying, "I'm really sorry that your child is dead." If they said, "She's not dead," then I would say, "I'm not going to fight about this. If you need to spend some time saying goodbye and having people come in before we turn machines off, that's fine." If the family then says, "Well, we're going to go to court," then I would let them go to court. I believe the court is making a bad decision if it says, "Well, the parents say the patient is not dead based on their religious beliefs." This also leads to the question of who will pay for keeping the body "alive." (Reviewer-).

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Keywords: End-of-Life Issues, Defining Death, Legal & Personal Struggles

Print Tag: Refer to original journal article

## Diversion a Growing Problem With Prescription Pain Meds

### *Prescription Pain Medications: Diversion.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

In the U.S., prescribed opiates are often diverted, either illegally or just because we sometimes take each other's meds. Diversion and tracking the prescribing of pain meds have come under increased scrutiny by law enforcement.

The prescribing of painkillers (opioids, OxyContin®, etc) has recently received a lot of attention in the press. How do we deal with patients who request pain medications? How do we decide whether they are drug seekers or are truly trying to get their pain relieved? If people are in pain, my job as a doctor is to try to help relieve their pain. Sometimes the best way to help with their pain is to use opiates. At other times, the best way to treat their pain is to *not* use opiates. The question for me--and all health care providers--is to determine if the patient presenting with pain (eg, he/she is uncomfortable and having distress) has a physiologic cause for that pain or whether the cause for the pain is due to an addiction disorder. This is often hard to differentiate.

**Diversion:** Another issue that has complicated the prescribing of pain medications in American society is the fact that prescribed opiates are often diverted, sometimes for illegal sales and sometimes because we take each other's medicines in America. The more opiates that are out there in society, the more likely that there are issues of diversion and illness, not in the patient, but due to others and due to use of those medicines. Diversion and tracking the prescribing of these medications are subjects that have come under increasing scrutiny from law enforcement. States can try to help decrease diversion via the use of state registries so doctors can see whether people are getting opiates from multiple places. The medical industry can decrease diversion by encouraging physicians to be more careful in their prescribing of opiates. Nonetheless, physicians are always going to need to use judgment in prescribing opiates. We should prescribe opiates only for cases in which the evidence supports their benefit. Therefore, as a society, we need (1) better research into whether opiates help certain pain syndromes and (2) better non-opiate treatments for those pain syndromes. In addition, non-opiate treatments need to be better supported by sound evidence. Often, complementary medicine, rehabilitation, or physical therapy often helps reduce the pain, but these treatments can be hard for patients to gain access to and for patients to afford. (Reviewer-).

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Keywords: Prescription Pain Medications, Diversion

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## Patient Goals Affect Choices in Informed Consent Process

*Ethical Issues: Informed Consent, Informed Refusal, and Therapeutic Privilege.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

Straightforward discussions with patients are important during the informed consent process. If a patient appears to make a "bad choice," then we should learn what his/her goals are and review the risks and benefits.

Informed consent is part of a process meant to help patients make informed decisions after discussing the risks and benefits of certain procedures or treatments. But how should the physician handle the situation in which the patient appears to make a bad decision? The first thing is, as the physician, to be curious: most people come to you because they *want* your help. If the patient is making what you consider to be a bad choice, then the question is, "What can I do to help them make a better choice?" The opposite of informed consent is informed refusal -- the patient listens to everything, appears to understand the risks, benefits, and options, and then says, "No, I don't want that." At that point, the physician can either let the patient's decision stand or the physician can try to understand the patient's perspective. We should not ask patients to be "little doctors." We should sit down with them, understand their goals, and then make recommendations. It can be helpful to our patients if we help them make better decisions. **Competency:** Is there a time when you, as the physician, want to challenge or test a patient's competency or capacity if he/she makes a "bad choice"? For me, the most straightforward approach to the situation is to ask the patient to help me understand what he/she is thinking about a given situation or topic. Then I try to talk him/her through that decision again. **Therapeutic Privilege:** Is there such a thing as "therapeutic privilege" in which you do not have to give the patient certain bits of information or complete information? I believe we should be really careful about the use of therapeutic privilege. I believe it is very important that, in general, we *do* try to talk about certain things. I would be very cautious about using therapeutic privilege as a way to say, "It is just too risky to talk about it." Often, when physicians invoke therapeutic privilege, it means that they have not practiced how to talk about this issue in a reasonable way with the patient. The notion of therapeutic privilege is contrary to patient autonomy and something that should either never be used or be used very rarely. **Ethics Consults:** When do you recommend that a doctor get an ethics consult? I believe that doctors get an ethics consult whenever they are struggling with making the appropriate decision and feels that talking to someone else would be helpful. (Reviewer-).

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Keywords: Medical Ethics, Informed Consent, Informed Refusal, Therapeutic Privilege

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## Peer Review Helps Ensure That Docs Adhere to Good Standards

*Peer Review: Patient Input, Physician Input, and an Overview of the Process.*

Robert M. Arnold, MD

Robert M. Arnold, MD -Special Presentation

During the peer-review process, 3 key elements must be established: (1) the standards of practice, (2) the physician being reviewed understands those standards, and (3) the physician is adhering to those standards.

The peer-review process is an important part of practicing medicine during which colleagues review one doctor's practice of medicine and then try to make recommendations for improvement. **Patient Input:** Typically, physicians review the quality of another doctor's medical practice standards during the peer-review process. A patient's input can also provide valuable information. For example, a layperson can often judge a doctor's communication skills, and whether he/she is polite, kind, and respectful in his/her interactions. However, it is difficult for patients to judge whether the doctor made the right therapeutic decision in a given situation. **Physician Input:** Physicians involved in the peer-review process are evaluating the degree to which the original physician is making decisions based on scientific evidence and best practice. I believe doctors should be able to do that to help the public feel confident that doctors are meeting ethical and clinical standards. Patients want to make sure that their doctor is doing a good job. **Process Overview:** During the peer-review process, 3 key elements must be established: (1) the standards of practice, (2) the physician being reviewed understands those standards, and (3) the physician is adhering to those standards. Establishing the standards of practice can come through clinical guidelines created by medical societies or advances in evidence-based medicine and making sure that the doctor treats similarly situated patients in the same manner. Understanding the standards of practice requires that all doctors inculcate themselves with them when they are medical students and incorporate them into their practices. In addition, physicians should ensure that they maintain their specialty certifications (if they have any) and that they maintain up-to-date core competencies. To evaluate adherence to those standards of practice is a difficult part of the peer-review process. Of course, the state medical boards are responsible for mandating the licensure requirements and making sure that people meet them. Physicians should do their own peer review through assessing their own practice, assessing their knowledge and skills through various methods such as certification, and assessing their practice performance through means such as credentialing when applying for hospital privileges. (Reviewer-).

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Keywords: Peer Review, Patient Input, Process Overview

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## Neurosurgery

### Volume 16 Number 2: Ethics 2015, Palliative Care & End-of-Life Decisions

Quiz Code: 33525P

**To complete the quiz for credit**, log onto [www.practicalreviews.com](http://www.practicalreviews.com). If you have not previously registered at the site, click on "New Customer Registration" located in the right navigational bar and follow the directions. You will need your account number (located above your name on the Table of Contents) and your mailing zip code. **To access the quiz**, click on the "Take a Quiz" link located in the right navigational bar. Enter the quiz code and select your answers. Once you click Submit, you will receive immediate notification of your score.

#### Quiz Questions

1. Hospice care is generally provided to patients who are receiving life-prolonging therapies for their illnesses.  
Circle one:    True                      False
2. In the U.S., national trends show that health care systems are doing a better job of developing palliative care programs to improve the care provided to seriously ill patients.  
Circle one:    True                      False
3. To be a palliative care specialist, a doctor must complete a year-long fellowship program.  
Circle one:    True                      False
4. In the U.S., approximately 90% of people aged >65 years have advance directives.  
Circle one:    True                      False
5. It is not ethically acceptable for patients to base their decisions regarding end-of-life care on the wishes of their family when that decision conflicts with their own desires.  
Circle one:    True                      False
6. When making decisions about a patient's end-of-life care, negotiation and compromise between the family and patient are not an acceptable means for reaching that decision.  
Circle one:    True                      False
7. Approximately 10% of Americans consider themselves to be vitalists who believe that life is worth living even if in a comatose state.  
Circle one:    True                      False
8. The term "futile care" is often used to describe health care that is very unlikely to succeed in providing the desired outcomes for the patient.  
Circle one:    True                      False
9. If a family requests that a patient not be told about a cancer diagnosis, then the medical provider should explain that he/she (the provider) must disclose the diagnosis to the patient, but it can be done in such a way that the patient can easily decline talking about it.  
Circle one:    True                      False
10. In 2015, California became the fifth U.S. state to legalize physician-aided dying.  
Circle one:    True                      False
11. According to the American Medical Association's Code of Medical Ethics, Opinion 2.211, physician-aided dying is fundamentally incompatible with the physician's role as a healer.  
Circle one:    True                      False
12. In Belgium, the number of euthanasia requests increased approximately 60% between 2007 and 2013.  
Circle one:    True                      False
13. Health care, with all its technical sophistication, truly remains a very human endeavor.  
Circle one:    True                      False
14. Patients can be declared dead via cardiopulmonary criteria (heart not functioning) and brain criteria (brain and brainstem not functioning).  
Circle one:    True                      False
15. The diversion of prescribed pain medications has come under increased scrutiny by law enforcement in the U.S.  
Circle one:    True                      False
16. Therapeutic privilege is contrary to patient autonomy and should either never be used or should be used very rarely.  
Circle one:    True                      False
17. Patient input provides no value to the peer-review process.  
Circle one:    True                      False

## Neurosurgery

### Answers for Volume 16 Number 1: Electronic Health Records 2015

Quiz Code: 33476P

1. F Users of an electronic health record system should report an IT-induced health-related incident only when it results in patient harm.
2. T In an analysis of medical malpractice claims in which electronic health records were a contributing factor, CRICO found that incorrect information in the EHR was among the most common issues identified.
3. T The U.S. military's contract for an EHR system requires that their system be interoperable with thousands of health care providers in the private sector.
4. T In the era of electronic health records, the official or legal medical record includes anything recorded regarding the treatment of a patient, including all data captured using any medical device.
5. T When an electronic health record data breach occurs, patients should be notified and warned to be wary of false income tax returns being filed on their behalf.
6. T When using templates to help document cases in the electronic health record, some specific details should be incorporated into each patient's record to reflect individualized care.
7. T When a list of patients is presented in an electronic health record system, a misclick of the mouse can redirect data to the wrong patient's record, thus creating a potential problem for both patients.
8. T When electronic signatures are used on consent forms, the signature space must not be on a screenshot by itself with no other consent-related text on the screen.
9. T Unless captured in the electronic health record, text messages between doctors concerning a patient's care may be difficult to use in the defense of a malpractice lawsuit.
10. F During the deposition for a malpractice case, the copy of the patient's medical record that is shown to the defending doctor will appear to be exactly the same as the record the physician saw while treating the patient.
11. T If a personal device, such as a cell phone, is used to take photos of a patient, the images should first be downloaded into the patient's chart and then deleted from the personal device.
12. T For patients hospitalized in high-tech smart rooms, all entries and exits to/from the room should be captured in the electronic health record, which may help prove that a doctor visited a patient at a particular time.
13. T In drug trials, an interface between electronic health records and electronic data capture systems used to compile trial data could avoid errors associated with compiling data.
14. T Predictive analytics are helping health care providers create targeted treatment measures for different populations.
15. F Predictive analytics is similar to traditional evidence-based medicine because both predict outcomes or medication requirements based on the group rather than on the individual.
16. T Data gathering via EHRs and the use of predictive analytics may change physicians' roles so that they act less like decision-makers and more like consultants for their patients.

**Neurosurgery**  
**Answers for Volume 15 Number 12: Meaningful Use 2015**  
Quiz Code: 33475P

1. T Meaningful use is an incentive-based program intended to help stimulate the adoption of electronic health records by eligible health care providers and hospitals in the United States.
2. T In the U.S. government's program to stimulate the use of electronic health record systems, a penalty phase eventually will be implemented that will reduce Medicare reimbursements to any eligible providers or hospitals not meeting Meaningful Use criteria.
3. T A "clinical decision support rule" is a series of electronic messages related to a patient's condition or disease that pop up on the computer screen to remind the provider of some potential piece of information he/she should know before proceeding.
4. T All certified electronic health record systems must have a portal that allows patients to securely log in and view their personal information online.
5. T To meet the Meaningful Use Stage 2 requirement that 5% of patients must use the EHR portal to submit medically meaningful questions to the physician, the average provider needs to have at least 50% of their patients signed up for using the portal.
6. T In Meaningful Use Stage 2, providers are required to give patients a Summary of Care at the end of each encounter.
7. T In public health terms, syndromic surveillance describes the monitoring of a disease as it changes over time in the population.
8. T Starting in 2016, the reporting of EHR activity will be based on the calendar year for all eligible providers and hospitals participating in the Meaningful Use program.
9. T Before our EHR systems can interface directly with the CMS system, interoperability between all systems must be established.
10. F At large institutions, all providers use uniform EHR systems, thus greatly simplifying the task of reporting Meaningful Use measures.
11. T In the Meaningful Use program, auditors are tasked with ensuring the accuracy and authenticity of the data being submitted to CMS.
12. F In Meaningful Use Stage 3, the electronic transmission of information through the use of faxing will continue to be acceptable.
13. T In the U.S., the top 5 vendors for electronic health record systems control about 70% of the ambulatory market.
14. F Meaningful Use Stage 3 specifically exempts telemedicine from needing to meet the core objectives of EHR use.
15. F The criteria for Meaningful Use Stage 3 published by January 2016 are final and cannot be modified before Stage 3 is implemented.
16. T Individuals who are considering selling their private practice to a large health system first need to ask the buyer to explain how they will help the physician meet Meaningful Use measures as well as other quality measures.