

Beyond Advance Directives

Importance of Communication Skills at the End of Life

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THE PATIENT'S STORY

Mr N was a 55-year-old man with a radiographic diagnosis of pancreatic cancer invasive to colon and liver; however, biopsy was nondiagnostic. Mr N met with his primary care physician, Dr W, and told him that he wanted to pursue a tissue diagnosis and consider anticancer treatment, yet he valued his physical functioning even at the expense of longevity. He wished to avoid being "hooked up to machines" for a prolonged period but would not commit to a do-not-resuscitate (DNR) order until a diagnosis of cancer was confirmed. Mr N told his physician that he preferred to pursue this workup at another hospital because he felt his diagnosis had been missed initially at his primary care physician's facility. Mr N made all of his decisions with the assistance of his daughter, Ms N.

While awaiting further diagnostic testing, Dr W referred the patient to his hospital's Palliative Care Clinic. Mr N expressed to the palliative care team that, above all else, he wished to remain comfortable and functional. He also stated that he was forcing himself to eat and required laxatives to initiate bowel movements. One week later, the patient returned to his primary care physician complaining of fatigue, anorexia, bloating, and worsening constipation. Concerned that he might be experiencing bowel obstruction, Dr W advised surgical consultation, and the patient said he would pursue that at his local hospital. Yet, this did not happen and several days later he presented to Dr W's hospital with increasing abdominal distension and pain and was admitted to the medical service. Abdominal radiographs showed no obstruction, and he was discharged after treatment with enemas, morphine, and steroids.

Four days later, Mr N was readmitted with similar symptoms. Again without radiographic evidence of obstruction, he was treated conservatively. On the third hospital day, after no improvement, surgical consultants recommended an abdominal computed tomographic (CT) scan. When asked by his physician what he would want done if his condition should deteriorate suddenly, Mr N said that he wished to be kept comfortable but would not rule out the

possibility of surgery. He remained reluctant to agree to a DNR order. Two days later, while still awaiting the CT scan, Mr N acutely developed severe abdominal pain and x-ray showed free air under the diaphragm. With consent from the patient's daughter, he was taken emergently to surgery. The surgeon, Dr V, discovered a perforated cecum and diffuse intra-abdominal carcinomatosis. A diverting procedure was performed, his abdomen was left open, and he was discharged to the intensive care unit (ICU), intubated and hypotensive.

Patients and their families struggle with myriad choices concerning medical treatments that frequently precede death. Advance directives have been proposed as a tool to facilitate end-of-life decision making, yet frequently fail to achieve this goal. In the context of the case of a man with metastatic cancer for whom an advance directive was unable to prevent a traumatic death, I review the challenges in creating and implementing advance directives, discuss factors that can affect clear decision making; including trust, uncertainty, emotion, hope, and the presence of multiple medical providers; and offer practical suggestions for physicians. Advance care planning remains a useful tool for approaching conversations with patients about the end of life. However, such planning should occur within a framework that emphasizes responding to patient and family emotions and focuses more on goals for care and less on specific treatments.

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Dr W spoke with the patient's daughter and ex-wife who were distraught at what they saw in the ICU and who felt that the patient would not have wanted to be kept alive in this situation. They said that 10 days earlier he had com-

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pleted an advance directive to this effect. His physician advised them to obtain a copy of this document prior to making any decisions but did not specifically address code status. Shortly thereafter, Mr N experienced a cardiac arrest and resuscitation was initiated. His daughter vigorously objected and placed herself between the code team and her father. Mr N spontaneously recovered a heart rhythm, but became agitated and gestured that he wanted the endotracheal tube removed. Urgent discussions were held regarding goals of care, and the family now produced the patient's advance directive, which named the patient's daughter and ex-wife as surrogate decision makers. With their approval, Mr N was sedated, the endotracheal tube was removed, and he died shortly thereafter with his family at the bedside.

Surgical pathology confirmed the diagnosis of metastatic moderately differentiated adenocarcinoma consistent with pancreatic origin.

Mr N's daughter, Ms N, his primary care physician, Dr W, and his surgeon, Dr V, were interviewed by a Perspectives editor in December 2003.

PERSPECTIVES

Ms N (the daughter): *[A]fter the surgery, they were hooking him up to everything and they couldn't give him pain meds because . . . his heart would stop. They just kept him hanging on in agonizing pain for hours, even though I had the do-not-resuscitate document in my hand.*

Dr W (primary care physician): *In a hypothetical way, he [had] said that he would not want his life prolonged if it meant that he could not be independent and live at home and speak with his family. During his stay in the hospital, I began to talk with him in a more urgent way about what he would like done if his situation should deteriorate acutely, in particular, if he developed a perforation or a true obstruction. Would he consider surgery now? He was very reluctant to make up his mind, even after extensive discussion.*

Dr V (surgeon): *The surgical team was not fully aware of anything that was going on with his condition. After the operation was the first time I had a chance to really talk and get a feeling of what [the family] knew and what they didn't know. I told them . . . that the prognosis was not very good. [Ms N] said that . . . her dad was going to be very disappointed if he ever woke up because this aggressive care was against his wishes. I tried to hide my shock and frustration.*

Patients and their families struggle with myriad choices concerning the medical care that precedes death, ranging from the aggressiveness of treatment to the site of care. These struggles may generate conflict and dissatisfaction with the medical team.^{1,2}

Clear decision making contributes to quality of life at the end of life, and its absence may lead to worse outcomes.^{3,4} Despite a series of conversations and, ultimately, the presence of a written advance directive, Mr N, his family, and his physicians struggled with decisions about his care, ending with traumatic conflict. Confusion about goals of care

and the inability to make certain decisions meant that Mr N experienced unnecessary pain.

Even when physicians and patients try to plan for the future, advance directives are easily misunderstood or misinterpreted.⁵ This discussion reviews challenges in creating and implementing advance directives; elucidates factors that affect clear decision making, including trust, uncertainty, affect, hope, and the presence of multiple medical providers; and offers practical techniques to ease decision making at the end of life.

Advance Directives—Promising But Insufficient

Ms N: *We had decided about 2 and a half months [earlier], do not resuscitate. We had consulted with an attorney who had drawn up papers. If my father could not have good quality of life, we agreed that it was selfish to have him here in a vegetative state or in pain constantly. We discussed this over and over again.*

Advance care planning is the process by which patients, together with their families and health care practitioners, consider their values and goals and articulate preferences for future care. Written advance directives formalize these preferences and include living wills or other statements of patient preferences and durable powers of attorney for health care, which name health care proxies. Do-not-resuscitate (DNR) orders are written by physicians to operationalize one specific set of preferences articulated by patients and their proxies. Unfortunately, with few exceptions, the introduction of advance directives and the federal Patient Self-Determination Act have had little demonstrated impact on resuscitation events.⁶⁻¹³ Some of the barriers to successful implementation have been procedural when, for example, documents are not available when needed. More importantly, problems arise with deciding in advance about specific interventions,¹⁴ the adequacy of communication,¹⁵ the willingness of health care providers to follow patient preferences,^{11,16} and patient and family misunderstandings about the process.

Both procedural and communication difficulties occurred with Mr N. First, the document his daughter referred to as a DNR order was in fact an advance directive form that stated only global preferences. Mr N clearly valued quality of life over quantity of life, but his physician was unsure whether the specific instance of perforated bowel met the patient's criteria for withholding aggressive treatment.

This case is unusual in the degree of conflict between family and physicians, but it helps to illustrate that advance directives are not the same as DNR orders and generally do not provide instruction for specific circumstances. Rather, they should facilitate discussions of goals of care and consideration of all of the elements of quality at the end of life from symptom control to limitation of treatment. Because some of this care may occur after the patient has lost decision-making capacity, such discussions about advance care planning should be held with the patient, family, and physician

together to permit discussion and clarification of treatment goals specific to the patient's condition.

Decision Making Must Be Responsive to Changing Scenarios

DR W: *While he was awaiting his CT scan, . . . his pressure dropped. He became unresponsive and was intubated. [After the surgery, the family was] distraught to see him in the ICU, with a tube in his mouth. They were questioning if this was what he would really want.*

DR V: *[T]he primary team attending came by, and I actually talked to him, as we were just about to walk out of the ER. He told me that the father didn't really want anything aggressive, but he hadn't really finished his conversation to the fullest extent. So, at that point, that was as much as I knew.*

This patient's outcome, including intubation in an ICU, resulted from his stated preferences. Mr N had been unable to decide against the surgery, perhaps holding out hope that he did not have metastatic cancer or that the operation would buy him some time. When confronted emergently about whether to operate, his daughter made choices consistent with her father's expressed wishes. On the other hand, despite the patient's presumed diagnosis before surgery, the likelihood of widespread carcinomatosis and slim chance of recovery apparently was not discussed with the daughter, making the postoperative course a disturbing surprise for the family. In the emergent situation, the surgeons likely knew little about his case, but discussing with the family the possibility that Mr N would not recover from surgery and the palliative care options would have better prepared the family for the eventual outcome.

After the surgery, the prognosis was clear. Since the family did not expect the eventual outcome, and the patient could not participate in the decision-making process, a family meeting was in order to allow clinical status, prognosis, and treatment goals to be reassessed, and if necessary modified. As new information emerges, decision making must be fluid.⁷⁻¹⁹ Time-limited trials of therapy can be very useful to assess whether particular interventions are effective while defining an end to that treatment if goals are not met.²⁰ Although communication could have been substantially improved and the family better prepared, ultimately Ms N appears to have acted as her father would have in consenting to the surgery, but then wanting withdrawal of support.²¹ The tragedy occurred when the withdrawal of support was delayed, and the patient underwent an unnecessary and traumatic resuscitation attempt.

When Is a Document Needed?

DR W: *[After the surgery, the family] mentioned that he had an advance directive, that a lawyer was working on it. I said that it would be really important to get that advance directive now. I went to my office, thinking I would get the fax. He went into an abnormal rhythm, and because he was still full code, . . . the MICU [medical ICU] team began resuscitation procedures.*

MS N: *He kept saying he was in pain, he was in pain. They called a code blue, . . . and I just started screaming, "Why won't you listen? I am giving the document that says he does not want this. He is in pain. He's talking through morphine telling you to let him die and you're ignoring his wishes."*

DR W: *[After the resuscitation] I had the advance directive. A no-code order was written by the MICU doctor. In one of the most horrendous experiences of my time as a physician, he kept trying to pull the tube out, saying that he was in a great deal of pain. The family decided that he didn't want the tube any more, and they decided to extubate him, which of course, was upsetting to the MICU team, which had just met him. I advised the MICU team that this was not a spur-of-the-moment decision on the part of the family or the patient. The tube was removed and he died not long after that.*

Unfortunately, DNR orders are frequently not written even when this is the patient's preference.^{16,22,23} If one thing could have been done differently to change the outcome of this case (apart from providing adequate pain control), it would have been to write the DNR order much earlier—ideally before the surgery, or certainly immediately after, when the diagnosis was clear.^{24,25} Resuscitation outcomes are extremely poor in the setting of metastatic malignancy.²⁶⁻²⁸ Once the operation was completed and the patient was in the ICU, there was no reason to hold up the DNR order waiting for the advance directive document.

Written advance directives are useful when there is disagreement within a family, when there is a conflict between the family and health care team, or when the patient assigns a nontraditional family member (eg, friend or same-sex partner) as the surrogate. If the patient's preferences are known and understood by the family and team through an oral advance directive, in most states the written document is superfluous. However, to facilitate communication among members of the health care team, it is important to document the patient's preferences and how they were determined.

Key Elements of Communication

Although Mr N's physicians talked to him and his family on multiple occasions about his illness, the likely prognosis, and options for care, ultimately the patient's decisions contributed to a tragic outcome. Factors in addition to words influence how the messages of a medical encounter are interpreted and can complicate a seemingly straightforward transaction.

Trust. MS N: *I think, in all honesty, that they were more interested in protecting their own jobs, not wanting to be responsible for my father's death.*

Trust, the confidence that one's health care provider is acting unfailingly in one's interest, is fundamental to effective medical care, particularly at the end of life. Ms N ascribed unprofessional motives to the physicians' actions, a belief that may have provoked her extraordinary response to the resuscitation attempt. Although conflict between provid-

Box 1. Establishing Trust With Hospitalized Patients

Taking care of patients in the hospital often requires physicians to develop relationships quickly and does not allow much time to engender trust through experience. The following may help:

Encourage Patients and Families to Talk

"Tell me what you understand about your illness."

"We've just met and there is so much going on with you right now. To help me get to know you better, can you tell me about your life outside of the hospital?"

"I'm sure that this illness has been a lot to absorb quickly. How are you coping with this?"

Do Not Contradict or Put Down Other Health Care Providers, Yet Recognize Patient Concerns

"I hear you saying that you didn't feel heard by the other doctors. I'd like to make sure that you have a chance to voice all of your concerns."

"It sounds like Dr Jones left you feeling very hopeful for a cure. I'm sure he really cares about you, and it would have been wonderful if things would have gone as well as he wished."

Acknowledge Errors

"You're absolutely right. Four days was too long to have to wait for the CT scan. Any excuses we have won't make you feel better."

Be Humble

"I really appreciate what you've shared with me about the side effects of the medication. It's clear that the approach I had suggested is not going to work for you."

Demonstrate Respect

"I am so impressed by how involved you've been with your father throughout this illness. I can tell how much you love him."

Do Not Force Decisions

"We've just had a very difficult conversation, and you and your family have a lot to think about. Let's meet again tomorrow and see how you're feeling about things then."

ers, patients, and families is not uncommon,²⁹ the establishment of trust fosters successful resolution of conflict through open and honest communication.^{2,20,29,30}

Frequently, a medical team and a hospitalized patient have not had a lengthy relationship, so physicians must rapidly create a trusting environment. In one study, women with cancer stated that feeling that a doctor cared for, understood, and respected them; gave them enough time; listened; and was open and honest encouraged them to trust physicians and accept their recommendations.³¹ Such communication can be accomplished quickly. Women who ob-

served an oncologist add 40 seconds of compassionate language to his usual encounter felt less anxious and thought the doctor cared more about the patient.³² The manner in which one interacts with a patient appears to be the most important factor to establishing trust.³³ An empathic, patient-centered style and a forum that permits an open discussion of grievances may be the best approach (BOX 1).³⁴

Uncertainty. DR W: *One of the things I learned is that presenting them with information is one thing, but assisting them in the decision making is another thing. I should have made much stronger recommendations.*

Had Mr N known for certain that he had metastatic cancer, he likely would have been inclined to accept a purely palliative approach to care and a DNR order. Had Ms N known about the likely outcome of surgery, she may have declined the intervention. However, the diagnosis and prognosis were only certain after surgery, and then she was able to make the decision to withhold further treatment.

Uncertainty characterizes all medical decision making, and physicians must help patients manage it.³⁵⁻³⁷ Surveys consistently show that most patients wish to receive as much information as possible,^{38,39} perhaps as a way to cope with uncertainty.^{36,37} However, patients who are at either extreme of preferences for decision making—those who want to be entirely in control of decisions and those who defer entirely to their physicians—are less satisfied⁴⁰ and are more anxious than those who take an intermediate role.⁴¹

This work suggests that most patients prefer to participate in decision making but wish to receive a physician's advice about recommended options. Physicians must find the balance between conveying the ambiguity that at times may cloud medical practice and helping patients find the best options for them.

On reflection, Mr N's physician believed that he could have given a clearer recommendation. Physicians tend to discuss uncertainty but frequently do not give recommendations,⁴² likely because of concerns about appearing overly paternalistic. However, such guidance is often welcome,^{39,41} particularly when based on the patient's elicited values.⁴³ In this case, the physician, aware of the patient's goals, might have advised him of the very low likelihood that certain courses of treatment would allow him to achieve these goals and could have strongly recommended a DNR order.

Affect. MS N: *It wasn't until I got emotional and started screaming and crying that anyone noticed. I don't think until then that they heard the concerns.*

Attention to affect, the feelings associated with the content of conversation, is key to resolving communication difficulties at the close of life.⁴⁴ After receiving bad news, most people are so emotionally overwhelmed that they are unable to comprehend very much about the details of the illness or treatment plan.^{45,46} Emotion affects processing; people who are in negative moods may pay more attention to the delivery than to the content of a message.^{47,48} Clinicians should attend to affect while sharing information to in-

crease the likelihood that patients will hear what they are trying to say. Unfortunately, conversations between physicians and patients often transpire only in the cognitive realm; physicians frequently miss opportunities to enter the ambit of emotions.⁴⁹⁻⁵¹

Rather than using facilitative communication techniques, such as open-ended questions or empathic responses when inquiring about psychosocial issues, studies have shown that physicians and nurses often impede discussion by changing the subject or ignoring these concerns.^{52,53} One study showed that, even in a hospice setting, only 40% of patient concerns were elicited.⁵⁴ Patients with cancer tend to disclose fewer than half of their concerns,^{53,54} leading physicians to inaccurately assess distress.⁵⁵ Communication techniques that are open-ended and focus on patients' and family members' emotional states are more likely to elicit patients' concerns about symptoms, which can then be treated (BOX 2).^{56,57}

In the present case, whether the patient's or his daughter's emotions were ever acknowledged directly is unknown. It is easy to imagine that Mr N's indecision was a function of coping, at a relatively young age, with a sudden and devastating diagnosis. Similarly, his daughter was grieving terribly as she was about to lose her father and yet was distracted with worry about contacting her lawyer to get the advance directive faxed. Statements such as "Are you feeling scared?" "This must be terribly hard," or "I can't imagine what you're going through, but I'm impressed with how you've been able to cope" name and acknowledge the emotion and could have been applied effectively earlier on. They align the physician with the patient prior to engaging in the difficulties of decision making.

Hope. Virtually no one wants to die. We may be able to promise the most peaceful of final days, but 55-year-old patients rarely acquiesce to death without a fight. Hope is the frame within which they construct their future. It may be a desire for a particular outcome, or it may be, more broadly, trust or reliance. Physicians rightfully struggle to promote hope in the patient with advanced disease and to support a positive outlook.⁵⁸ Yet such an approach is frequently accompanied by an unjustified fear that discussing death may distress patients.⁵⁸⁻⁶² Physicians frequently convey overly optimistic prognoses or do not give this information at all.⁶³ Fearing the loss of hope, patients frequently cope by expressing denial and may be unwilling to hear what is said.⁶⁴ Patients with more optimistic assessments of their own prognosis are more likely to choose aggressive therapies at the end of life.^{18,65}

Physicians should recognize that it is not their job to "correct" the patient's hope for a miracle.⁶⁶ The key question is whether this hope is interfering with appropriate planning and behavior. Clinicians, at their best, can provide an empathic, reflective presence that will help patients marshal and draw strength from their existing resources (BOX 3). Together, the physician and the patient can "hope for the best but prepare for the worst."⁶⁷ Helping the patient and family

Box 2. Attending to Patient Affect

Conversations about end-of-life treatment issues are emotionally charged, and it is hard for patients and families to make these decisions without first processing some of the accompanying emotions. Health care providers can assist the decision-making process by consciously attending and responding to the affect that arises during these discussions.

Acknowledge the Emotion

"Is talking about these issues difficult for you?"

"Making these decisions on your father's behalf is not easy. I wonder if it sometimes feels overwhelming?"

Identify Loss

"I bet it's hard to imagine life without your father—I can see how close you are to him."

Legitimize the Feelings

"It's quite common for someone in your situation to have a hard time making these decisions—it can feel like quite an enormous responsibility."

"Of course, talking about this makes you feel sad—it wouldn't be normal if it didn't."

Offer Support

"No matter what the road holds ahead, I'm going to be there with you."

Explore

"You just mentioned feeling scared. Can you tell me more about what scares you most?"

manage their hope and their resources in a realistic way may leave the family in the best possible shape after their loss.

Communication Among Multiple Providers

MS N: *I think that if the doctors who were working in the ICU and the emergency department had more communication with the palliative care team that would have been better because we had discussed over and over again my father's wish for a good quality of life. It kind of goes null and void when you have a whole new set of doctors who . . . just come in and start treating the patient.*

DR V: *Most times in surgery, unless we are specifically, explicitly told not to go ahead and give the most care to keep somebody alive, that's what we do. Since I was so late to this situation, I didn't know enough to step back and say, "What are we doing?" When I talked to another doctor who had seen the patient about 2 weeks earlier, he said that they had the discussions with the family, but they were never completed. This could have been prevented. His suffering could have been prevented. The terrible taste in everyone's mouth could have been prevented.*

Sharing medical information and coordinating care by multiple physicians can be challenging. Working collaboratively to honor a patient's preferences is even more diffi-

Box 3. Communicating With Hope

Talking about treatment choices at the end of life does not necessarily rob patients of hope. Redirecting the patient's goal toward realistic hopes and being present with compassion can serve as powerful acts in helping patients make decisions while maintaining a hopeful outlook. The following phrases may help:

Hope for the Best But Prepare for the Worst

"Have you thought about what might happen if things don't go as you wish? Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for most."

Reframe Hope

"I know you are hoping that your disease will be cured. Are there other things that you want to focus on?"

"I wish, too, that this disease would just stay in remission. If we can not make that happen, what other shorter-term goals might we work toward?"

Focus on the Positive

"We've been talking about some treatments that are really not going to be effective and that we don't recommend you use. But there are a lot of things we can still do to help you—let's focus on those."

"What sorts of things are left undone for you? Let's talk about how we might be able to make these happen."

cult when providers become involved only late in the illness and during emergencies. Collaboration requires clear, consistent, physician-to-physician communication. Chart notes should include lucid discussions about patient preferences and goals for care, and, during critical illness, regular family meetings with the entire care team.^{68,69} It is useful to begin such meetings with a statement such as, "Over the past couple of days, a lot of doctors have been involved with your (or your loved one's) care. Tell me what others have been telling you about the illness."

Although the burden of maintaining continuity in our health care system ought not fall on patients and families, physicians can suggest that they keep notes from meetings with their physicians, share these with subsequent clinicians, and request that physicians communicate with each other to increase the likelihood that preferences will be honored.

From a systems perspective, electronic medical records provide a potential solution.⁷⁰ For example, the Veterans Health Administration electronic medical record system allows placement of clinical warnings that link to progress notes, DNR orders, and scanned advance directive documents. Another successful intervention is the Physician Order for Life Sustaining Treatment (POLST), a preprinted and signed physician's order specifying treatment instructions in the event of serious illness, including cardiopulmonary resuscitation, lev-

els of medical intervention, antibiotics, intravenous fluids, and feeding tubes.^{71,72} Used for community-dwelling frail elderly persons and those living in nursing homes, care has been consistent with the form in more than 80% of cases studied,^{71,72} and their specificity yields greater success at achieving palliative care goals than do advance directives.

CONCLUSION

This case is an extreme example of what can go wrong when advance care planning takes the form of nonspecific discussions and documentation as opposed to directed discussion with the physician about the patient's condition and facts of the case. Misunderstandings remain about the role and applicability of advance directive documents, and interpretation of preferences may be difficult when overshadowed by questions of uncertainty, trust, affect, and hope. Physicians can learn from this experience to not take all preferences at face value or as being static and to find ways to explore the complexities that underlie decision making. Choices can be offered in the form of recommendations that do not strip patients of their autonomy.

Advance care planning, in its broadest sense, is an important tool for physicians and their patients. However, such planning should occur within a framework that recognizes the emotions inherent in such significant decisions and focuses more on goals and less on directing specific treatments. In this sense, we must go beyond advance directives to truly meet the needs of patients making difficult decisions.

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Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at <http://www.jama.com>.

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OTHER RESOURCES

American Academy of Hospice and Palliative Medicine

<http://www.aahpm.org>

Palliative care physician membership organization provides conferences and other tools to assist health care providers communicating with patients at the end of life.

American Academy on Physician and Patient

<http://www.physicianpatient.org>

This society, devoted to the enhancement of physician-patient communication, hosts an annual course on communication skills training.

End of Life/Palliative Education Resource Center (EPERC)

<http://www.eperc.mcw.edu>

Online site with peer-reviewed educational resources, including materials on communication and end-of-life decision making.

Growth House Inc

<http://www.growthhouse.org>

Online information clearinghouse for all information related to end-of-life care.

OncoTalk

<http://www.oncotalk.info>

National Cancer Institute supported biannual retreat for oncology fellows to improve communication skills at the end of life.

Center for Palliative Care

<http://www.va.gov/durham/palliative/palliative.asp>

Research and education devoted to physician-patient communication and end-of-life care provides research and teaching resources.

The Center for Palliative Care Education

<http://depts.washington.edu/pallcare>

Well-organized compendium of educational resources with a particular focus on caring for patients with AIDS.