

Quality of Life Matters[®]

End-of-life care news & clinical findings for physicians

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Words Matter: How to Reframe Common 'Bad News' Phrases for More Effective Communication and Improved Care

Expressions commonly used without forethought to convey bad news or elicit a care plan for terminally ill patients are often truncated, inaccurate, or downright untrue — and as such can cause unintended harm, according to a palliative care expert who has proposed a set of alternatives for clinicians.

“Banishing [these] phrases...and replacing them with phrases that truthfully communicate the care that clinicians are able and ready to provide promotes clear understanding, elicits patient concerns that can be discussed, and emphasizes the enduring nature of the patient-physician relationship,” writes Steven Z. Pantilat, MD,

in an article published in the *Journal of the American Medical Association*.

PHRASES WITH POTENTIAL TO CAUSE HARM INCLUDE:

- “There is nothing more to do.”
- “Would you like us to do everything possible?”
- “Stop the machines”
- “Withdrawal of care”

What the physician means by these phrases is not always what the patient hears. While understanding can be improved simply by completing the sentence aloud (e.g., “There is nothing more to do...to cure the

illness.”) and by giving specifics, the clinician must also make clear that he/she is on the patient’s side and will proactively address options based on patient wishes.

WHAT PHYSICIANS CAN SAY INSTEAD:

- “I wish there were something we could do to cure your illness. Let’s focus on what we can do to help you.”
- “How were you hoping we could help? Would you like us to do everything possible to help you achieve your goal?”
- “We will stop the breathing machine and

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Physician Discussion of Hospice Increases Likelihood of Hospice Use Fivefold

Many patients who might benefit are not receiving these discussions

Older patients with advanced disease whose physicians discuss the option of hospice care with them are five times more likely to use this service than are patients whose physicians never broach the topic, a team of Yale University researchers has found.

However, the researchers also found that very few of the patients who could benefit from these discussions are actually receiving them. The reasons most frequently given by physicians for not discussing hospice are: the patient was “not terminally

ill” (50%) and the “prognosis was too uncertain” (37%). Yet, more than half the patients died during the course of the two-year study.

“Regardless of patients’ decision to use hospice, the discussion itself is important for patients with advanced illness, so they know the options available as their disease progresses,” write the authors of the report published in the *Journal of General Internal Medicine*. “Through conversations about services that may be available to the

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use medicines to make his breathing comfortable.”

- “We will begin the withdrawal of mechanical ventilation and vasopressors and the institution of comfort measures.”

Below, the author examines in detail each of these commonly used “shorthand” phrases, pointing out their potential for unintended negative consequences, then offers a more positive alternative for each, based on clinical observation.

Pantilat is director of the Palliative Care Program of the Division of Hospital Medicine, Department of Medicine, at the University of California, San Francisco. Pantilat notes that in California, state law mandates that patients who receive a diagnosis of a terminal illness or a prognosis of less than one year to live be provided with the opportunity to access information and counseling about end-of-life options.

There is nothing more to do.

Why this statement can be harmful:

- It is not true. “There is always something that can be done for the patient, despite an inability to achieve cure,” states Pantilat.
- It can place the patient and physician on opposing sides in a fruitless argument about treatments to cure the cancer.
- The patient may interpret it as abandonment, thinking the physician’s role has ended.
- Using this phrase can cement the physician’s mistaken belief that there *is* nothing more to offer the patient.

Say instead:

I wish there were something we could do to cure your illness. Let’s focus on what we can do to help you.

Would you like us to do everything possible?

This question is likely to be silently completed very differently by physicians and patients. By “everything possible” physicians might envision the complete array of available medical interventions, regardless of whether they privately consider them likely to improve the quality of time left. Patients might be thinking of symptom control and the support needed to achieve their goals in

the time remaining. This mismatch of unspoken assumptions can lead to the initiation of interventions contrary to the patient’s goals.

Say instead:

How were you hoping we could help? Would you like us to do everything possible to help you achieve your goals?

We will stop the breathing machine and the antibiotics, and if his heart stops, we won’t try to resuscitate.

Summarizing the decision to withdraw or withhold unwanted life-prolonging interventions in this manner focuses only on what will *not* be done. Stopping these measures, however desirable, is not stopping care. Physicians would do well to make clear to families that the care plan will now be actively refocused on biomedical and psychosocial measures to promote comfort.

Say instead:

To respect his wishes, we will stop the breathing machine and use medicines to make his breathing comfortable.” Or, of cardiopulmonary resuscitation: “If your heart stops, we will let you die peacefully.

Withdrawal of care

This is a phrase often used by clinicians and consultants as shorthand for the withdrawal of life-sustaining interventions. Like “stop the machines,” it carries the connotation that medical care not focused on survival is no care at all. Clinicians are advised to state accurately which interventions will be withdrawn and which measures will be initiated, thus reminding the entire care team that care of this patient will continue.

Say instead:

We will begin the withdrawal of mechanical ventilation and vasopressors and the institution of comfort measures.

Source: “Communicating with Seriously Ill Patients: Better Words to Say,” Journal of the American Medical Association; March 25, 2009; 301(12):1279-1281. Pantilat SZ; Palliative Care Program, Division of Hospital Medicine, Department of Medicine, University of California, San Francisco.

Major Epidemiologic Study of In-Hospital CPR in the Elderly Shows No Improvement in Survival Rate

Survival rates for elderly patients who received CPR in a hospital setting have changed little in recent years. Incidence of in-hospital CPR also remained steady for these patients, in spite of "...increased education and awareness about the limits of CPR in patients with advanced chronic disease and life-threatening acute disease."

That is according to a large epidemiologic study that examined data from 1992 to 2005 to determine the percentage of patients aged 65 and older (n=433,985) who received CPR in a hospital and survived to be discharged from the hospital. Findings were published in *The New England Journal of Medicine*.

Investigators found that CPR was performed in 2.73 of every 1000 hospital admissions, and 18.3% of these patients survived to discharge. Of those who survived, the percentage discharged to home decreased steadily during the study period.

Although the incidence of CPR did not increase during the study period, the percentage of patients who died in hospitals after receiving CPR increased by 37% between 1992 (3.8%) and 2005 (5.2%).

Incidence of CPR was higher and the survival rate lower for black and other non-white patients than for white patients. CPR was administered in 2.53 per 1000 hospital admissions for white patients, compared

with 4.35 per 1000 for black patients. The survival rate for white patients was 19.2%, compared with 14.3% for black patients. Such disparities might reflect the high intensity of care at end of life that is more common among black patients because DNR orders may be less common in this population, the authors point out.

Researchers conclude by urging clinicians to mention survival statistics when discussing DNR preferences with elderly patients.

Source: "Epidemiologic Study of In-Hospital Cardiopulmonary Resuscitation in the Elderly," The New England Journal of Medicine, 2009; 361:22-31. Ehlenbach WK, et al; Harborview Medical Center, University of Washington, Seattle.

Physician Discussion of Hospice Increases Likelihood of Hospice Use Fivefold

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patient in the future, the clinician may help the patient come to terms with the illness and aid the patient's transition from being seriously ill to dying."

The team conducted in-home interviews at four-month intervals for up to two years with 215 patients (age, 60 years or older) with a primary diagnosis of cancer, chronic pulmonary obstructive disease (COPD), or heart failure (HF). Participating physicians completed a questionnaire every six months regarding their estimate of life expectancy and any discussion of hospice with the patient.

KEY FINDINGS INCLUDE:

- Overall, only 22% of patients had a hospice discussion with their physicians (cancer patients, 46%; COPD patients, 10%; and HF patients, 7%).
- 73% of patients who received a hos-

pice discussion ultimately enrolled in hospice, while only 14% of patients with no discussion used hospice. Physician discussion was found to independently increase the likelihood of hospice use (OR, 5.3; 95% confidence interval, 2.3-13).

- 56% of the patients died during the study course. Of these, 40% had been given a life expectancy estimate of >1 year within 6 months of death (cancer patients, 11%; COPD or HF patients, 68%).

Physician estimate of patient life expectancy as <1 year was the independent variable most strongly associated with hospice discussion (OR, 13; 95% CI, 4.3-39). Patients were much more optimistic about their life expectancy than were their physicians; while only 10% of patients believed they had <1 year to live, nearly half of physicians estimated their patients' life ex-

pectancy as such.

Only 14% of patients whose physicians had estimated their life expectancy as <1 year said they were aware of hospice as an alternative to hospitalization.

"The results of this study, showing that patients are largely unaware of alternatives to standard treatment and that clinicians' discussion of hospice is determined largely by their perceptions and level of certainty regarding patient life expectancy, suggest that many patients who could benefit from such a discussion are not receiving it," the authors conclude.

Source: "Understanding Their Options: Determinants of Hospice Discussion for Older Persons with Advanced Illness," Journal of General Internal Medicine; August 2009; 24(8):923-928. Thomas JM, O'Leary JR, Fried TR; Yale University School of Medicine; Program on Aging and Department of Medicine, Yale University School of Medicine; New Haven, Connecticut; Clinical Epidemiology Research Center, VA Connecticut Healthcare System, West Haven, Connecticut.

Focus on Suffering: Physicians Offered Tips for Detecting and Preventing Patient Distress

Suffering can often go undetected in the clinical setting for several reasons: it is personal, it is more complex than pain or other symptoms alone, and physicians do not always have the training and/or experience needed to detect its presence.

Yet identifying and treating suffering is a key element of patient care. That is according to the authors of a recent study that compared physician perception with patient experience of suffering, and a keynote address given at the national assembly of specialists in hospice and palliative medicine. Their findings, comments, and suggestions are presented below.

PHYSICIANS' PERCEPTIONS OF SUFFERING

Despite a commitment to compassionate care, physicians may miss signs of substantial suffering in their patients, according to a study presented as the first to compare physicians' estimates of patient suffering with the patients' own ratings of their suffering during the same clinical encounter.

"For the majority of the domains of suffering that we asked respondents to evaluate, physicians did not accurately perceive the magnitude to which that domain contributed to the suffering experienced by

their patients," write the authors of a report published in *Academic Medicine*.

The researchers analyzed the matched survey responses of 227 patients with chronic, serious, or life-altering illness and their treating physicians at two teaching hospitals and several outpatient clinics in the Washington, DC, area. Each patient had been seen an average of six times by the matched physician prior to the survey.

In their earlier pilot study, the team had identified six major domains of suffering: pain, physically nonpainful symptoms, emotional suffering, systems factors, communication issues, and loss.

KEY FINDINGS:

- Only 30% of the patient-physician responses were concordant, although physician performance was better in the outpatient setting.
- Physicians treating inpatients significantly underestimated the contribution of milder emotional, physically nonpainful, and loss issues to the suffering of their patients.
- All physicians overestimated the impact of systems factors and communication issues on patient suffering.

"Failure to recognize and address the

extent and causation of patient suffering diminishes rapport and compromises therapeutic effect and overall satisfaction with care," write the authors.

"Physicians' recognition of suffering may not only enhance our appreciation for one aspect of meaning in their patients' lives, but also enhance the physicians' pleasure of successful treatment by feeling, as deeply as possible, the patient's pain and the proactive efforts to relieve it." The authors call for further patient-physician studies and offer suggestions to "narrow the gap" in the physician-patient understanding of suffering. [See sidebar, below, left.]

Source: "The Accuracy of Physicians' Perceptions of Patients' Suffering: Findings from Two Teaching Hospitals," *Academic Medicine*; 84(5):636-642. Lesho E, Foster L, Wang Z, Sarmiento D, Dennison S, Vahey MT, Nolan E, Smalls C; Division of Bacterial and Rickettsial Diseases, Walter Reed Army Institute of Research, Silver Spring, Maryland; National Naval Medical Center, Bethesda, Maryland.

THE IMPORTANCE OF ADDRESSING SUFFERING

Understanding the impact of pain and suffering on the whole person and treating each patient as an individual — not just a disease — was the topic of the opening plenary session of the March 2009 annual assembly of the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association.

"Physicians are not bystanders; they are there to make people feel better," declared Eric Cassell, MD, professor emeritus of public health at Weill Medical College of Cornell University, New York, and attending physician at New York-Presbyterian Hospital.

Cassell emphasized the importance of finding the cause of pain and of under-

Detecting the Cause of Suffering: What to Keep in Mind

- Don't assume that what you consider to be the worst aspect of a patient's illness or condition is the cause of the patient's greatest suffering.
- Remember that "little things could mean a lot." Even seemingly mild physical nonpainful symptoms can cause great suffering, wear down patience, and erode the healing process for a patient.
- Explore the nature of patients' suffering directly. Ask specific questions, e.g., "I know your [cancer, stroke, etc.] must be terrible, but is there some aspect of your illness, no matter how small or seemingly irrelevant, that is causing you to suffer and that I might be able to help you with?"

— Adapted from Lesho, et al, *Academic Medicine*

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RESEARCH MONITOR

Life Support Decision-Making: Physician Communication with Surrogates Is Key

Among surrogate decision makers for incapacitated patients, there is little consensus over whether physicians should make recommendations regarding the decision to limit life support. A recent study published in the *American Journal of Respiratory Critical Care Medicine* explores surrogate attitudes toward physician recommendations.

Researchers showed surrogates (n=165) a video of a simulated conversation between a physician and a surrogate, including two different endings — one in which the physician does not offer a recommendation regarding limiting life support, and the other in which the physician does.

Each surrogate was interviewed to determine the ending he or she preferred and the reasons for these preferences. Overall results included:

- 56% preferred that the physician make a recommendation.
- 42% preferred that the physician not make a recommendation.
- 2% of surrogates considered either ap-

Should Physicians Make a Recommendation? Communication Is Key

1. Ask the surrogate if he or she wants a recommendation. If the answer is yes, treat the recommendation as a starting point for the decision-making process.
2. Be flexible. Value the unique needs of each surrogate.
3. Be aware of ethical arguments regarding physician involvement in decision making.

— White, et al, *American Journal of Respiratory Critical Care Medicine*

proach acceptable.

Surrogates also shared perceptions in four key areas: the appropriate role of the physician, the consequences of physician recommendations, how the recommendation affects the decision-making process, and how the recommendation affects long-term regret for families.

Surrogates who preferred that the phy-

sician make a recommendation tended to feel that a recommendation was part of the physician's central role and could take away some of the pressure of the decision making. They also felt that the physician's opinion could help them reach an informed decision, while avoiding regret over the decision in the future.

Among surrogates who preferred that the physician not make a recommendation, many expressed the opinion that a physician recommendation was not appropriate and could negatively affect both the surrogate's emotional state and the physician-surrogate relationship. Many also felt that the opinion of the physician would weigh too strongly in the decision-making process, and that this influence could cause the family eventually to regret the decision to limit life support.

Source: "Are Physicians' Recommendations to Limit Life Support Beneficial or Burdensome?" *American Journal of Respiratory Critical Care Medicine*; 80:320-325. White DB, Evans LR, Bautista CA, Luce JM, Lo B; Division of Pulmonary and Critical Care Medicine, University of California, San Francisco.

Focus on Suffering (from page 4)

standing what the experience of pain and other symptoms mean to the patient. "The meaning of distress is as important as the symptoms themselves," he stated.

Cassell said he was aiming his comments at physicians, rather than the politically correct "clinicians," and offered suggestions for achieving the goal of medicine: making people feel better. [See sidebar, right.] "If you treat all sick patients this way, you have a very good chance of preventing suffering," he concluded.

For further information, visit the academy's website at www.aahpm.org.

Tips for Preventing Suffering

- **Be present.** For you to be present, *you must be present.* Running off or being focused on a pager will not help the patient.
- **Touch.** When you are there and concerned, the reassurance of human touch is natural, and can help calm the patient's fears.
- **Listen.** An attentive listener does not leave until he or she is sure of what was said, and stores that information for future visits.
- **Remember the family.** Look after the family, too, because they will be the ones suffering when the patient dies.
- **Prognosticate.** Predict what will happen with the patient's symptoms, and explain why. You won't always be right, but making that effort will help address their suffering.

— Adapted from Eric Cassell, MD, Address to the AAHPM/HPNA 2009 Annual Assembly

Palliative Care Can Benefit Heart Failure Patients Throughout Course of Illness

Providing palliative care immediately after diagnosis of heart failure, while simultaneously providing life-prolonging treatments, can improve quality of life for patients. However, many clinicians do not offer palliative care because of concerns that patients may associate palliative care with end-of-life care.

That is according to the authors of a study published in the *Journal of Palliative Medicine*. Although palliative care originated as a complement to hospice care at end of life, many clinicians and organizations now consider palliative care to be a philosophy of care that should be offered to patients and families throughout the course of any life-limiting illness, note the authors.

Palliative care can offer supportive measures such as advance care planning assistance, symptom management, education about the disease, and psychological and spiritual support for patients and families. However, most patients and family caregivers are not familiar with the term and therefore do not automatically associate it with end of life, the authors point out.

Investigators set out to determine the factors that both facilitate and inhibit the use of palliative care for advanced heart failure patients, from the perspectives of:

- **Scientific literature:** Very few articles — 14 in 10 years — have discussed the merits of using palliative care for patients with heart failure before the end-of-life phase.
- **Attitudes of healthcare providers:** Of six advanced practice/research nurses interviewed, four strongly associated palliative care with end of life; two had broader concepts of palliative care. Of three heart failure physicians interviewed, all saw the value of palliative

Communicating with Heart Failure Patients and Families

1. Plan how to deliver sad or unexpected news. Give the patient advance notice that you have bad news.
2. Use the ask-tell-ask model. First ask what the patient understands, then correct any misunderstandings, and tell your information. Ask what questions they have, and clarify the information you have given them.
3. Use simple, honest language and simple statistics, and ground the data in more than one way. Define any medical terms you use, and use numbers, such as “1 out of 5 people...” Describe the chances of both death and life.
4. Hope for the best, but plan for the worst. Ask what the patient hopes for, and express what you hope for. Plan for death or other bad outcomes, using phrases such as “If things do not go as we hope.” Address both possibilities.
5. Put the uncertainty into a normal context. By using phrases such as “like many things in life,” you can reference the inherent uncertainty of life.
6. Make sure the patient understands that you or your team will work with them to meet specific goals.
7. Deliver length of life in a broad range, such as “months to years,” allowing for error in either direction.
8. Empathize with the patient by describing your own emotions, and identify the patient’s possible emotions, such as sadness, anger, or surprise.
9. Summarize the plan of treatment, and schedule a follow-up appointment.

— Goodlin, *Journal of the American College of Cardiology*

care for heart failure patients but were concerned that patients would perceive palliative care as end-of-life care. Clinicians did report discussing advance directives early in the disease and providing “both financial and family counseling throughout the disease process.”

- **Spousal caregivers of heart failure patients:** The majority of spouses (26 out of 38) had never heard the term palliative care; however, those who did know the term were likely to associate it with end of life. Once they understood the definition, all caregivers saw the value of palliative care at some point during the course of the disease.

In a related article published in the *Journal of the American College of Cardiology*, Sarah J. Goodlin, MD, writes that “comprehensive care” for heart failure pa-

tients should address palliative needs such as patients’ distress over symptoms and psychosocial or existential issues, and that it should provide strategies for coping with heart failure, while simultaneously treating the disease with evidence-based disease-modifying interventions.

Goodlin further states, “Communication with the patient and family and patient-centered decision making are integral to palliative care.” She offers practical tips for communicating with heart failure patients and families. [See sidebar, above.]

Sources: “Heart Failure and Palliative Care: Implications in Practice,” *Journal of Palliative Medicine*; 12(6):531-536. Hupcey JE, Penrod J, Fogg J; School of Nursing, Penn State University, Hershey and University Park, Pennsylvania. “Palliative Care in Heart Failure,” *Journal of the American College of Cardiology*; 54(5):386-396. Goodlin SJ; *Patient-Centered Education and Research*, Salt Lake City, Utah.

CLINICIAN RESOURCES

Storing Advance Directives Online Improves Accessibility for Patients, Families, Physicians

Caring Connections, a program developed and managed by the National Hospice and Palliative Care Organization (NHPCO), has partnered with Google Health™ to make advance care planning more accessible to individuals. Patients can use a computer to download advance directive forms — both living wills and health care power of attorney forms — from Caring Connections and then store the completed forms in a personal, secure Google Health account online.

Both downloading the forms and storing them online are free of charge. In addition, patients can store and organize any other health information using the same Google Health account, and they can specify email addresses of family members, health care decision makers, and medical professionals who will have access to the information stored in the Google Health record.

Advance directives allow patients to document their wishes regarding the types of care they would like to receive if they are not able to express their wishes at the time of an illness. However, sometimes even when a patient has completed advance directive forms, the forms are not available when a health care emergency occurs. Online storage can make the documents readily available.

The Caring Connections website (www.caringinfo.org) provides access to advance directive forms for all 50 states and the District of Columbia. The website also offers other valuable information for patients and families, such as advice on communicating with family members and physicians about end-of-life care preferences, resources for caregivers, and information about the multidisciplinary benefits of palliative care and hospice care.

How to Store Advance Directive Forms on Google Health

1. At www.caringinfo.org/googlehealth, select **Find your state-specific advance directives here.**
2. Select your state from the list.
3. Print the instructions and forms that are displayed.
4. Complete and sign the forms.
5. Scan the completed forms and store them on your computer.
6. At www.google.com/health, either log in to your existing account, or create a new account. (If you have a Google account for email or other services, you can log in with that account and then accept the terms for Google Health.)
7. On the Google Health home page, select **Files and images** from the list of links on the left side of the screen.
8. Upload your scanned forms from your computer.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

The EPEC Project (Education in Palliative and End-of-Life Care)

www.nhpc.org

National Hospice & Palliative Care Organization

www.caringinfo.org

Caring Connections: National Consumer Engagement Initiative to Improve End-of Life Care

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/palliativecare.htm

Medical College of Wisconsin Palliative Care Center

www.painpolicy.wisc.edu

University of Wisconsin Pain and Policy Studies Group

www.capc.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center

End-of-Life Care Meetings for Clinicians

Pain Management. December 5-12, 2009, Hawaiian Islands cruise from Honolulu. Sponsor: Continuing Education, Inc. Accredited by the Accreditation Council for Continuing Medical Education. Mail: 5700 4th St. N., St. Petersburg, FL, 33703; Phone: 800-422-0711; Email: contactus@continuingeducation.net; Website: www.continuingeducation.net

26th Annual Meeting of the American Academy of Pain Medicine. February 3-6, 2010, Henry B. Gonzalez Convention Center, San Antonio, TX. Website: www.painmed.org/annual_mtg/index.html

Annual Assembly of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. March 3-6, 2010, Boston, MA. Phone: 847-375-4712; Fax: 847-375-6475; Email: info@aahpm.org; Website: www.aahpm.org

Program in Palliative Care Education and Practice (Spring and Fall). April 27-May 4 and November 10-16, 2010, Cambridge, MA. Sponsor: The Harvard Medical School Center for Palliative Care. Phone: 617-582-7859; Fax: 617-632-6180; Email: pallcare@partners.org; Website: www.hms.harvard.edu/cdi/pallcare/index.htm

29th Annual Scientific Meeting of the American Pain Society. May 12-15, 2010, Walt Disney Swan & Dolphin Hotel, Orlando, FL. Phone: 847-375-4715; Fax: 866-574-2654, or 847-375-6480; Email: info@ampainsoc.org; Website: www.ampainsoc.org

ADVERTISE YOUR HOSPICE HERE

For more information about hospice and palliative care, or to make a referral, please contact your local hospice and palliative care organization.

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