WEEK OF APRIL 1, 2009

CLINICIANS' WORDS AND TONES "HUGELY AFFECT PATIENTS"

Author Steven Z. Panilat, MD, of the University of California, San Francisco, writing in the current *JAMA*, says, "Words matter. … Although poor communication may harm patients by leading to unwanted invasive procedures, generating unnecessary anxiety, or creating feelings of abandonment, good communication can improve outcomes for patients and their families by promoting shared decision making and addressing patient concerns."

Panilat cites a recent study which described "a novel communication model" and a process by which clinicians could use it. He writes, "The 4 parts of this model include seeing communication as a process that unfolds over many conversations, taking a patient-based approach to understand the patient's values, making recommendations, and using positive and negative role models and experience to develop an effective personal approach to communication. … Many of these recommendations can be used daily to prevent poor communication and unfortunate choices of words that can create unintended and negative consequences."

Parnilat takes four "common and problematic" phrases and describes their "potentially negative effects on patients, families, and clinicians." Rather than use these phrases, he suggests "a lexicon aimed at improving communication based on clinical observation."

The first of these four phrases is **"There is nothing more to do." Clinicians "rarely articulate" the end of that phrase – "to cure the illness" – leaving patients and families with the belief that "the clinician has nothing left to offer." Parnilat says that the statement is never true, as something can always be done for the patient, even if a cure can't be effected.** The physician may not be prepared to provide palliative care, but even for patients very near death, symptom management and psychosocial support can "ensure comfort and ease suffering."

The phrase also leaves physicians and patients in a tug-of-war, with the patient insisting on further treatment, and the physician insisting that there is none. The patient may feel abandoned, and "this phrase cements the clinician's mistaken belief that there is nothing left to offer."

Better phrases might be, "I *wish* there were something we could do to cure your illness," and "Let's focus on what we *can* do to help you." Parnilat says, "The suggested phrases not only model specific language, but by having the clinician address options, encourage a more detailed discussion of what can help."

The second phrase is **"Would you like us to do everything possible?" This question usually gets a "yes" answer, which "likely evokes a radically different scenario for clinicians than for patients."** Clinicians may see "the complete armamentarium of medical interventions," while patients and families have in mind relief of pain or another particular goal.

Parnilat calls this question "inartful," and says it's more effective to ask, "How were you hoping we could help?" He adds, "Regardless of the response, the clinician should ask additional questions and offer options to clarify the patient's preferences and goals. Starting with an open-ended question and continuing with options sets the stage for an accurate understanding of the patient's preferences, elucidates and manages expectations about the efficacy of the available options, avoids any misunderstanding about the meaning of 'everything possible,' and encourages the patient to share emotions and concerns."

The third phrase is **"Stop the machines." Framing the discussion of withdrawing or withholding interventions frames the issue "on what will *not* be done, rather than on the care that will be provided," Parnilat says.** "This singular emphasis on stopping fails to acknowledge and detail how the clinician intends to refocus both the biomedical and psychosocial plan of care with measures intended to provide comfort rather than prolong life."

Parnilat suggests, "When discussing the withdrawal of mechanical ventilation, the clinician can say, 'To respect his wishes, we will stop the breathing machine and use medicines to make his breathing comfortable.' Similarly, a discussion of cardiopulmonary resuscitation can be articulated as, 'If your heart stops, we will let you die peacefully.' Each of these phrases provides not only alternative words to say but reframes the act of stopping into one of actively promoting the patient's goals, and the former further explains the new treatments that will be instituted."

The fourth phrase is using "withdrawal of care" when talking with consultants. **In speaking with consultants, clinicians may use this to communicate something similar to "stop the machines." Parnilat says that this "reinforces the idea that the only real way to care for the patient is with treatments focused on survival.** Clinicians should avoid the shorthand 'withdrawal of care,' and instead say, 'Withdrawal of mechanical ventilation and vasopressors and institution of comfort measures,' which accurately reflects the speaker's intent and reminds all clinicians caring for the patient that their care will continue."

In conclusion, Parnilat writes, "Communication is a powerful instrument to convey the myriad forms of caring and is an important tool. Banishing phrases like 'There is nothing more we can do,' 'Would you like us to do everything possible?' 'Stop the machines,' and 'withdrawal of care' 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. A new lexicon that provides models for effective communication may lead to fewer misunderstandings, improved care, and increased satisfaction for patients and clinicians. Phrases with potentially pernicious consequences should be replaced with better words." (*JAMA*, 2009;309(12):1279-1281)

PUBLIC POLICY NOTES

* **Declining revenues have lawmakers in several states calling "for more legal leeway in sentencing, bail and parole as a cost-control measure." At least 23 states and the District of Columbia allow judges to put terminally ill prisoners in hospices or nursing homes in some circumstances.** Many county jails do not have infirmaries, and must pay hospital costs for inmates who cannot be cared for in the jails. **Once prisoners are out of legal custody, states and counties are not responsible for their healthcare costs, which usually are picked up by Medicare or Medicaid.** (*phillyBurbs.com*, 3/23)

* **Washington Governor Chris Gregoire (D) has proposed cutting 80% of the budget of the state's electronic registry of end-of-life directives.** *The Seattle Times* article says, "Savings from scaling back the registry would barely dent the deficit. In fact, registry supporters argue the proposed cuts could well cost the state more money in the long run if patients are given expensive treatments they did not want." (*The Seattle Times*, 3/28)

* **NHPCO has provided its members with a Wage Index Chart and Wage Index Calculator that accurately reflects the CMS FY09 Wage Index rates that were revised to account for the moratorium on the BNAF.** (*NHPCO E-mail*, 3/27)

* **In its recent annual report to Congress, MedPAC "concluded that home health agencies have been paid significantly more than their cost of providing the services in recent years.** Their average margins were about 16.5 percent a year between 2002 and 2007, and, even after some rate adjustments, are expected to exceed 12 percent this year in the midst of a recession." **A report by the GAO said that "the overpayment problem is exacerbated by fraud and manipulation."** (*The New York Times*, 3/23)

* **Kurt Perry, of Chicago, had planned his own final exit with the support of the Final Exit Network. When law enforcement shut down Final Exit less than 24 hours before Perry's planned suicide, the plans he'd been laying for three years were disrupted.** Two Final Exit "guides" had supported him emotionally for much of that time, and he wanted them present, but not involved, when he would "hasten his death." Rosalie Guttman, one of his guides, is "relieved he hasn't gone through with it yet," but says that "he, and everyone, has to consider the window of opportunity" – the time "when they are suffering but still physically able to kill themselves without direct aid." (*Chicago Tribune*, 3/22)

* ***The Atlanta Journal-Constitution*** **interviewed Ted Goodwin, Final Exit founder who was recently charged with assisting the suicide of a Cumming, Georgia, man.** Goodwin says that he founded Final Exit after his father's death from emphysema. His father refused hospice because he didn't want strangers in his house, and his father's doctor refused to take Goodwin's phone calls. He says he "came to learn that the medical profession can be very unfeeling, very unsympathetic when people are in real crisis." (*The Atlanta Journal-Constitution*, 3/22)

* **University of Florida researchers say that a pilot program that allows palliative care for seriously ill children from the time of diagnosis can change the utilization rates for pediatric hospice care.** Florida's Partners in Care program allows children on Medicaid or SCHIP to enroll in hospice at the time of diagnosis, and between 2005 and 2008, program enrollment increased from 80 patients to 486. (*The Sun-Sentinel*, 3/24)

* **As the federal government signals a more lenient stance toward the use of medical marijuana, several states are considering allowing it.** The New Hampshire House passed such a bill last week, 234-138, and it has gone to the Senate. Other states with medical marijuana bills in their legislatures include New Jersey, Illinois and Minnesota. (*USA Today*, 3/25

RESEARCH & RESOURCE NOTES

* **"Efforts Aim to Curb Opioid Deaths, Injuries," in the current *JAMA*, examines the efforts of several groups to increase the safety of opioid prescriptions for chronic non-cancer pain.** A new guideline for the use of such opioids "urges physicians to carefully screen patients before prescribing opioid medication, … perform a physical and obtain a medical history, including any individual or family history of substance abuse, … and use that information to weigh the risks and benefits for each patient and to determine whether an opioid drug would be appropriate." (*JAMA*; 2009;301(12):1213-1215)

* ***Medscape* interviewed Stephen D. Passik, PhD, of Sloan-Kettering Memorial Cancer Center and Cornell University Medical Center, on barriers to optimal pain management.** The article is online at www.medscape.com/viewarticle/589841. *Medscape* requires a one-time, free registration. (*Medscape*, 3/25)

HOSPICE NOTES

* **George Mark Children's House, the only free-standing hospice and respite-care center for children in the US, is facing such a severe drop in donations that it only has operating funds through June.** An article in *The Los Angeles Times* says, "George Mark's failure would be a blow to their prospects and to a medical discipline, which, at 10 years old in the United States, is still as youthful as many of its patients." Dr. Barbara Sourkes, director of palliative care at Lucille Packard Children's Hospital in Stanford, says, "It would be devastating for the whole newly emerging field of pediatric palliative care. Across the country, George Mark stands for so much. It would send an absolutely terrible message." (*The Los Angeles Times*, 3/28)

* **A letter to "Dr. Bea" in *The Connecticut Post* gave Dr. Beata Skudlarska, a Bridgeport geriatrician, the opportunity to explain and recommend hospice care.** The questioner had heard from a friend that hospice was no help to her dying mother. Dr. Bea responded, "I suspect that for your neighbor friend and her mom, hospice help came too late to show a benefit. That is yet another paradox, because hospice gets involved so late

and because families and patients are rarely told the truth about the disease by their doctors many people believe that hospice 'causes' death! Nothing is farther from the truth. Hospice also does not leave the families after the final moment happens, but rather helps with the grieving process as well." (*The Connecticut Post*, 3/23)

* **Ava Jo Rowton-Hall, who is an aide with Harry Hynes Memorial Hospice in Wichita, Kansas, was preparing a bath for patient Sandra Watts when she noticed smoke in the home. She and Watts escaped the home, and Watts is now living with family.** Watts calls Rowton-Hall her "guardian angel." (*KAKE*, 3/25)

* **In a brief article in *The Des Moines Register*, Palliative Care Association of Iowa executive director Rebecca J. Anthony says, "President Barack Obama's call for an overhaul of our nation's health-care system has triggered a national debate on what works and what doesn't, including how Medicare dollars are spent. It's an appropriate time to highlight a part of our health-care sector that works, specifically hospice."** Anthony adds, "Hospice has been found to be the high-quality care that patients and families want, with more than 98 percent of served families willing to recommend hospice to others." (*The Des Moines Register*, 3/24)

NURSING SHORTAGE NOTES

* **The Orlando unemployment rate is double what it was a year ago, and higher than at any time in the last 32 years, but there is still a nursing shortage in the area.** An article in the *Orlando Sentinel* says, "The Florida Center for Nursing estimates that the Sunshine State will have a shortage of more than 18,400 nurses by next year — and more than 52,200 a decade from now." (*Orlando Sentinel*, 3/23)

* **The severe nursing shortage in Texas is "fueled by population growth and a lack of nursing faculty," the Texas Nursing Workforce Shortage Coalition says.** The group wants $60 million from the legislature to "dramatically increase the number of nurse graduates." (*San Antonio Express-News*, 3/26)

* **While employers would like to import more foreign nurses to fill the thousands of vacant jobs, "labor and nursing officials would rather see more energy spent on training nurses domestically." President Obama is clear on where he stands on the issue. "The notion that we would have to import nurses makes absolutely no sense," he said.** "There are a lot of people (in the U.S.) who would love to be in that helping profession, and yet we just aren't providing the resources to get them trained—that's something that we've got to fix. That should be a no-brainer." (*Modern Healthcare*, 3/23)

OTHER NOTES

* **In Philadelphia, NewCourtland is a nonprofit group that provides housing and services for senior citizens. Their new residential facility, NewCourtland Square, has**

motion sensors on the walls and other sensors that monitor kitchen activity, how long residents remain in the bathroom, and when they go to bed. If something is out of the ordinary, a computer calls the apartment, and if no one answers, human help is sent. NewCourtland has started a for-profit company, Healthsense, to sell the monitoring equipment to other institutions. (*The Philadelphia Inquirer*, 3/22)

* **Steve Hopcraft, of Compassion and Choices in Sacramento, says that his organization has come up with a model letter for dying patients to give to doctors if they want assistance in ending their own lives.** The letter "tells the physician your values and beliefs and says, 'If I am incapacitated, here is what I want you to do.'" He suggests talking to your physician ahead of time, and asking which options the physician will support based on his or her religious values. (*The Orange County Register*, 3/25)

Editor's Note: **"Self-care of Physicians Caring for Patients at the End of Life," in last week's *JAMA,* with a note in last weeks HNN, will be covered more fully if and when space allows.** (*JAMA*, 2009;301(11):1155-1164)

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