COMMUNICATING WITH DYING PATIENTS — Steven Z. Pantilat, MD, Associate Professor of Clinical Medicine and Director, Palliative Care Service and Palliative Care Leadership Center, University of California, San Francisco School of Medicine

Introductory remarks: communication can be difficult, even when talking about everyday issues and using same words; when we start talking about issues like death and dying, prognosis, advanced care planning, suffering, and spiritual concerns, communication becomes even more difficult, and when dealing with patients with whom we do not share common language, it can be more difficult yet

Communicating about illness and death: patients want to talk about these issues, but studies suggest that physicians do not communicate with patients about illness and death as well as they might

Recommendations for Improving Communication

Listen: speaker likes to ask broad open-ended question (eg, “how have things been going for you”), then give patient time (≈2 min) to respond uninterrupted (typically, patients in primary care outpatient practice get to speak for ≈18 sec before being interrupted by physician); often, most important thing patient wants to say to physician not first thing he or she says; open-ended question actually extremely effective way of taking patient history (shown to be more efficient than close-ended questions)

Make empathic statements: on average, seriously ill patient makes 2 to 3 statements each visit that have emotional content (fear of illness worsening; anger); important for physician to offer empathic reply that reflects patient’s emotion (eg, “I can see that what you’re facing is a scary experience, it must be petrifying”; “it must be really scary to think about being that sick”); if unable to identify emotion underlying patient’s statement, can respond with, “tell me more about that”; if one does not know what to say, even silence better than making unempathic statement; speaker listens for these types of statements, as they provide great opportunity to connect with patient, to establish rapport and trust, and to let patient know he is trying to understand his or her experience; if you misinterpret emotions behind statement (patient will correct you, but also will give you points for trying to understand)

Eliciting values and goals of care: not easy; patients tend to speak to physicians in language of what they do in their lives (eg, “I want to be able to go back to work”; “I want to be able to live independently”), while physicians often speak in language of what they do to patients (eg, “do you want to be in the intensive care unit [ICU]?”; “do you want to be intubated?”); challenge for physicians to interpret their language so that it speaks to language of patients; asking for specific intervention directives not helpful; need to elicit from patients outcomes important to them and what they value in their lives; may be specific issues (eg, cardiopulmonary resuscitation [CPR]) that need to be discussed with hospitalized patients, but should be done in context of overall values and goals; recommended phrases for eliciting values and goals — “when you think about what lies ahead, what worries you the most?”; “when you think about the future, what do you hope for?”

Offer prognosis: prediction difficult; cannot know exactly what will happen to patient; yet, physicians often have much more information than they are willing to acknowledge; reasons physicians do not like to offer prognosis — patients want physicians to be overly accurate; physicians do not want to take away hope; reasons to talk about prognosis — withholding prognosis can allow patient to have false hope (false hope is no hope); patients often want to know (true that patients want prognosis to be positive, but they also want information); absent explicit discussions, patients have to infer; information influences decisions; accuracy not critical; “we would all live our lives differently if we knew we had only one year to live”; not suggesting physicians should discuss prognosis with every patient; in considering whom to talk to, speaker asks himself “would I be surprised if this patient died in the next year?”

Discuss death explicitly: keep in mind that seriously ill patients already have thought about death and dying (for many patients, first thought after being given diagnosis of serious condition, eg, cancer, stroke, heart attack is, “I am going to die”); if physician can ask right question, it opens door for patient to talk about this, which can be great relief; even if patient not yet ready to talk about death and dying, important for him or her to know physician willing and ready to talk when he or she has questions; that said, death and dying not easy to talk about; speaker’s approach — “many patients with cancer tell me they think about the possibility of dying; they have questions about this; how about you?”

Remain sensitive to patient’s culture: throughout United States, physicians have patients from many cultures, including cultures in which talking explicitly about death and dying or about prognosis not valued as in dominant western culture; cultural issues — desire for information varies with culture; best response is for physicians to be curious and respectful of patients’ cultures and practices; patients usually know more than we (or their families) think they do; can discuss death and dying or prognosis in third person; ask how doctor in patient’s culture would handle information

Informed refusal: patients can waive their rights to information about their condition; however, need to hear refusal directly from patient, not just take it at face value from patient’s family; speaker’s approach — “I have information about your condition; some patients want to know the details, others prefer to have me talk to someone else; how do you feel?” (this statement gives patient opportunity to request that speaker talk instead to, eg, family member such as spouse or child [which he is happy to do if that is what patient truly wants], and lets speaker hear request directly from patient)

Communicating with patients approaching end of life: establish what patient and family already know about his or her illness; be aware of nonverbal communication (one’s own as well as patient’s); during these conversations, important to sit down in presence of patient; use “I wish” statements (helps to put physician and patient on same side); realize this cannot be just one conversation, but often series of conversations that unfold over time as patient’s status and ideas change; prepare and practice (evidence shows that how bad news presented has impact on patient’s psychologic outcome, independent of quality of news)
Language to avoid: “there is nothing more we can do”; “would you like us to do everything possible?”; “withdrawal of care”

Supporting Family Caregivers at the End of Life—Michael W. Rabow, MD, Associate Professor of Clinical Medicine, University of California, San Francisco, School of Medicine

Introductory remarks: case scenario of Mr. R (patient with pancreatic cancer); increasingly, death preceded by family caregiving; family caregivers provide “whole host” of supports for seriously ill patient (transportation; shopping; homemaking; emotional support; nutritional care; financial management); what is physician’s responsibility or opportunity for supporting family caregivers at end of patient’s life?

Burdens of Family Caregiving

Time and logistics: takes up great deal of time (20% of caregivers provide full-time or constant care; nearly 60% feel on duty 24 hr/day; treatment itself adds to burden of time); commitment unpredictable (determined by length of patient’s illness and functional decline); enormous administrative and logistical needs associated with caregiving (most caregivers report it “feels like reinventing the wheel”)

Physical tasks: physically difficult; caregivers typically elderly, may be ill or disabled; usually untrained (do not know how to move or lift patient); consequently, at significant risk for physical injury

Financial costs: huge uncompensated financial burden (outright expenses and lost income and benefits); economic disruption (20% of caregivers quit work to care for loved ones; nearly 33% of families lose all their income); worse for black and Hispanic families; similar regardless of insurance coverage; government support limited (Family Medical Leave Act provides only for unpaid leave to care for seriously ill family member; only few states allow eligible Medicaid personal care benefits to be paid to family caregiver); patients and families feel differently about costs of caregiving (patients fear being burden; families almost always willing to do anything); economic worries influence end-of-life care decisions (more likely to request comfort care only or consider physician-assisted suicide if feeling financial strain)

Mental health risks: huge; while caregivers certainly feel positive emotions (eg, satisfaction, increased feelings of intimacy), they can experience many negative emotions as well (eg, inadequacy; no matter how good caregivers are, they invariably feel they are not doing enough); risk for depression and anxiety high (50% of caregivers suffer from clinical depression; incidence probably even higher among those providing care >20 hr/wk); caregivers at greater risk for complicated grief if unprepared for patient’s death

Physical health risks: caregivers tend to put needs of ill person ahead of their own (minimize severity of their own problems; forego or delay their own healthcare; especially true for those with poor baseline health, limited education, or significant social isolation); health risks (decline in immune function; accelerated aging; worsened mental health status; increased cancer and mortality risks)

Physician’s role: physicians clearly have role with family caregivers (but role unclear); your patient may be family (physicians who question their patient populations will find large number at home caring for individual even sicker than they are; your patient’s family may need your attention as well); relationship can be intense (family members can challenge physician’s authority; may disagree among themselves; there may be specter of litigation; family may be culturally or religiously different from physician)

The bare minimum: physicians legally required to—address wishes of appropriate surrogate decision makers; report suspected neglect or abuse

Basic care: recognize instrumental role of family caregivers; basic assessment of caregivers (ask questions like “how is it going at home?”; “how are things going with you?”); most family caregivers berated by their loved one’s physician for not giving medications properly (without getting much appreciation for what they do); at very minimum, must have clear communication when “handing off” patients, between hospital and outpatient setting, and with families (to help them understand what is going on)

Advanced doctoring: in 1993, American Medical Association (AMA) stated that “the primary care physician has a key link—advanced doctoring, assessing the caregiver as well as the patient in a comprehensive home-based approach that includes training caregivers, validating the caregiver’s role, and case management”; physician in relationship with family caregivers

Activities Physicians Can Pursue to Support Caregivers

Excellent communication: family needs to know physician comfortable talking about death; family communication needs—physician willing to talk; timely and clear information (information needs paramount [patients and families tend to want prognostic information more than they want to make decisions; want control over timing of information]; physicians can provide proactive guidance); physician able to listen (elicit family’s views with open-ended questions; keep in mind difference between cognitive and communication; need to be sensitive to emotions behind caregiver’s cognitive questions and/or statements)

Advance care planning and decision making: studies have shown that documents (eg, verbal power of attorney, advance directives) do not have much influence on care; more important to make plans for care based on patient’s goals and values than to make decisions; diversity in decision making (57% of Korean-Americans see family as primary decision maker rather than patient; 45% of Mexican Americans; 24% of blacks; physician needs to recognize and be sensitive to this possibility)

Support for home care and hospice: family is medical team in home; provides incredible amount of medical services (20% of caregivers do dressing changes; 40% administer medications [of those, 50% administer ≥5 medications]; one sixth manage nonoral medicines; caregivers asked to make sophisticated medical assessments (when to give prn medications; when to call physician; when to take patient to emergency department [ED])

Physician’s role in home care: write clear guidelines for medications (eg, rather than “prn,” can write “offer and refuse”); let caregivers know whom to call for help and when; make sure caregivers part of well integrated interdisciplinary team; orient and prepare caregivers

Benefits of hospice: often ideal system for home care at end of patient’s life; initiates and coordinates multiple services; associated with clear reduction in risk of death of bereaved spouse; benefits may occur even when hospice care as short as 3 to 4 wk

Empathy for family relationships and emotions: increasing closeness and intimacy clearly one of benefits of family caregiving; emotional strain—increased risk for illness and anxiety; reinforced dynamics of families that were estranged (leading to forced reestablishment of ties); threats to dignity

Physician’s role in caregiver emotions: validate common feelings; reassure families about quality of care; listen to caregiver needs and opinions; recommend interventions that can lessen caregiver burden and improve satisfaction (adult day care; caregiver education; social work referrals; psychological support)

Attention to anticipatory grief and bereavement: research shows that support provided to caregivers before patient’s death more important than support provided to family members when already bereaved; known that when caregivers unprepared for loved one’s death, they are more at risk for complicated or traumatic grief
Educational Objectives

The goal of this activity is to review end of life care, with a focus on communicating with dying patients and supporting family caregivers. After hearing and assimilating this program, the clinician will be better able to:

1. Utilize techniques such as effective listening, open-ended questions, empathic statements, and eliciting values and goals in communicating with patients.
2. Cite the reasons physicians are often reluctant to offer a prognosis and the reasons they should do so when talking with patients at the end of life.
3. Talk explicitly about issues of death and dying, while remaining sensitive to factors such as cultural differences and nonverbal communication.
4. Discuss the role of family caregivers and describe the 5 burdens of family caregiving.
5. Consider and pursue opportunities to offer support and care to family caregivers who are caring for loved ones at the end of life.

Notes

Discussed on This Program

Atorvastatin calcium [Lipitor]

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Suggested Reading


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END-OF-LIFE CARE

On a Test and Evaluation form, complete Pretest section before listening and Posttest section after listening.

1. A good way to improve communication with patients is to ask broad open-ended questions and give the patient time to respond. Typically, patients in a primary care outpatient practice get to speak for _______ before being interrupted by the physician.
   (A) ≥2 min       (B) ≥75 sec       (C) ≥30 sec       (D) ≥18 sec

2. Often, the most important thing a patient wants to say to his or her physician ______ the first thing he or she says.
   (A) Is           (B) Is not

3. Asking open-ended questions is a good way to encourage the seriously ill patient to talk about what is on his or her mind. As a way of taking a patient history, open-ended questions are _______ than close-ended questions.
   (A) More efficient, even when time is considered
   (B) More efficient in every way but time
   (C) Effective but less efficient

4. On average, the seriously ill patient makes 2 to 3 statements each visit that have emotional content. If unsure how to respond, it is better to risk an unempathic statement than remain silent.
   (A) True         (B) False

5. In speaking with the seriously ill patient about his or her future care, it is most important and helpful to elicit:
   (A) The patient’s overall values and goals of care
   (B) Specific intervention directives

6. One of the burdens of caregiving for a seriously ill loved one is the time involved. It is estimated that about _______ of family caregivers provide full time or constant care, while almost _______ feel on duty 24 hr/day.
   (A) 50%; 80%       (B) 33%; 50%       (C) 25%; 75%       (D) 20%; 60%

7. Family caregivers are typically:
   (A) Elderly       (B) Middle aged     (C) Young adults

8. Choose the incorrect statement about the financial costs associated with family health care.
   (A) Uncompensated financial burden results from outright expenses and lost income
   (B) Burden similar, regardless of insurance coverage
   (C) Patients and family members have similar feelings about costs of caregiving
   (D) Economic worries influence end-of-life care decisions

9. One of the keys to good communication with patients and their family caregivers is that families and patients tend to want _______ more than they want _______.
   (A) Prognostic information; to make decisions
   (B) To make decisions; prognostic information

10. Hospice is:
    (A) Often an ideal system for home care at the end of life
    (B) Associated with a clear reduction in the risk for death of a bereaved spouse
    (C) Beneficial even when used for as little as 3 to 4 wk
    (D) A, B, and C

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