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Difficult Conversations: From Diagnosis to Death

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ABSTRACT

Background: Communication is the cornerstone of good multidisciplinary medical care, and the impact of conversations about diagnosis, treatment, and prognosis is indisputable. Healthcare providers must be able to have difficult conversations that accurately describe diagnostic procedures, treatment goals, and the benefits and/or risks involved.

Methods: This paper reviews the literature about the importance of communication in delivering bad news, the status of communication training, communication strategies, and psychosocial interventions.

Results: Although many published guidelines address difficult communication, communication training is lacking. Consequently, many clinicians may have difficulties with, or in the worst-case scenario, avoid delivering bad news and discussing end-of-life treatment. Clinicians also struggle with how to have the last conversation with a patient and how to support patient autonomy when they disagree with a patient's choices.

Conclusion: There is a clinical imperative to educate physicians and other healthcare workers on how to effectively deliver information about a patient's health status, diagnostic avenues to be explored, and decisions to be made at critical health junctions. Knowing how to implement the most rudimentary techniques of motivational interviewing, solution-focused brief therapy, and cognitive behavioral therapy can help physicians facilitate conversations of the most difficult type to generate positive change in patients and families and to help them make decisions that minimize end-of-life distress.

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INTRODUCTION

Coping with a life-limiting disease is never simple or easy. Helping patients and families make decisions about what constitutes good quality of life and when to discontinue aggressive treatment is one of a physician's most difficult tasks.[1] To be effective, clinicians must use a multitude of communication strategies and techniques to deliver information about the disease process, treatments, and prognosis, but practitioners currently receive little to no formal training in communication. Complicating the situation, many patients have difficulty accepting the gravity and importance of a life-limiting diagnosis. This resistance can result in a lack of focus and, more critically, the inability to achieve appropriate goals. With such patients, using traditional communication strategies and methods is often insufficient.

This paper reviews literature about the importance of communication in delivering bad news, the status of communication training, communication strategies, and psychosocial interventions that can be effectively used with patients at the end of life and with their families.

COMMUNICATION: THE CORNERSTONE OF CARE

Communication is the cornerstone of good multidisciplinary medical care. The impact of conversations about diagnosis, treatment, and prognosis is indisputable. The manner in which this information is delivered creates the framework for patients and families to approach what will eventually become their final journey.[2-5] Miscommunications among staff, family, and patients are common during the course of an illness and adversely affect patient care and quality of life. Without clear, goal-directed communication, care loses its purpose. When the purpose of care (aggressive treatment or quality of life preservation) becomes muddied or even lost in an unfortunate battle of wills, distress is certain to occur in patients, families, and caregivers.

Whether a clinician is a general practitioner, oncologist, or palliative consultant, many communication challenges arise, including demands from patients' relatives, intense emotions, troublesome doctor-patient relationships, insufficient clarification

of patients' problems, promises that cannot be kept, feelings of helplessness, too close involvement, and insufficient anticipation of various scenarios.[6] Several other factors also have an impact on communication: the lack of large comfortable consultation rooms to foster group discussions, busy clinic schedules that seldom leave time for in-depth conversations, and the hard-to-negotiate balance between personal attention and billable hours.[7]

A wealth of information exists on how to deliver bad news to patients and families, how to discuss end-of-life treatment and care, and how to talk to patients who are dying.[8-46] Saying goodbye from a patient's perspective is also well described. As an example, *The Last Lecture* by Randy Pausch[47,48] artfully lays out life lessons intended for his young children to revisit as growing adults. Chochinov's dignity therapy [49-52] is a novel therapeutic approach to assist patients and their families in dealing with end-of-life issues. However, no article or chapter of text instructs physicians and other healthcare workers on how to approach the last encounter with a patient who is actively dying.

A life-limiting illness is not a single event. The critical phases of an illness can be thought of as a linear process: diagnosis of an ultimately fatal disease, initiation of aggressive life-prolonging treatment, recurrence of the disease, and the end-of-life stage. However, coming to grips with a life-limiting diagnosis is rarely a linear process for patients. Within each of these phases exists the significant possibility of distress for patients and their families. However, just as the possibility of distress exists, so too does the opportunity to change a patient's perception of the illness through the appropriate use of communication strategies and techniques.

TRAINING STATUS AND NEEDS

Implicit in the training of physicians and other healthcare workers is a need to effectively and accurately communicate the reality of diagnostic procedures, treatment goals, and what benefits and/or risks are involved. However, communication during the course of an illness is often impeded because clinicians have not been taught the necessary skills. Practitioners currently receive little to no formal training on how the information they provide to patients must change at different times in the treatment trajectory. Very little has been written about the impact miscommunication has on the decision-making process or the patient-healthcare provider relationship.

An emergent body of data suggests that the death of a patient can have powerful effects on physicians in training.[53-58] However, residents and palliative care fellows receive very little instruction in the practice of empirically validated methods of therapy and communication.[59-61] There is a paucity of data on how to direct difficult conversations to specific goals and to deal with patients who are unwilling to acknowledge their ultimate prognosis.

The Accreditation Council for Graduate Medical Education (ACGME) defines training requirements for all medical areas, and interpersonal and communication skills is one of the six ACGME competencies. Hematologists-oncologists are expected to gain experience in palliative care, including symptom management and appropriateness of hospice referral, yet the specific details of such experience are not well defined.

Programs at 2 medical education providers in Louisiana demonstrate the minimal formal training practitioners receive on saying goodbye to a patient for the last time. Louisiana State University Health Sciences Center in New Orleans offers a 3-month nonacademic end-of-life elective to second-year medical students. Students who apply for this elective meet during their personal time to learn about end-of-life care issues and effective ways to deliver bad news. The curriculum discusses medical and emotional management of the dying patient but does not address the physician's approach to the last encounter. A palliative care elective at Louisiana's largest nonprofit health system uses the 2005 Back et al[62] article, "On saying goodbye: acknowledging the end of the patient-physician relationship with patients who are near death," as its sole point of reference.

Falcone, Claxton, and Marshall note that skills-based training is needed across all levels of medical residency,[63] and patient communication skills need to be taught as part of residency training. Such graduate medical education programs should be based on the adult learning model.[64-66]

COMMUNICATION STRATEGIES AND TECHNIQUES

Dealing with end-of-life issues can be stressful for physicians and other healthcare providers and devastating for the family and friends of a dying patient. Several models of communication strategies, crossing many disciplines in medicine and psychology, suggest how to effectively deliver this information. The communication program, Oncotalk, developed for oncology physicians, provides a structure and template to help improve communication with patients and families.[67] The SPIKES model[18] (setting up the interview, assessing patient perception, obtaining a patient's invitation, giving knowledge and information to a patient, addressing a patient's emotions with empathetic responses, and providing a strategy and summary) can be implemented by any healthcare

professional. This 6-step protocol provides the framework for the health professional to deliver bad news about the diagnosis or prognosis in a manner that a patient and/or family can find as palatable as possible.

Other models to assist the clinician in delivering information about diagnosis, treatment, and prognosis share the basic components of the SPIKES model: (1) be prepared by knowing the disease, its natural course, and treatments that have been given; (2) find out what the patient and family know; (3) secure an invitation to discuss these matters and fire a warning shot to prepare the patient for the discussion that is to follow; (4) provide the important facts the patient and family need to know with an appropriate manner and language; (5) deal with the emotions that this information occasions; and (6) have a plan.

PSYCHOSOCIAL INTERVENTIONS

Comprehensive care of a patient with a life-limiting condition necessitates the integration of psychological and social (psychosocial) aspects of care into the overall assessment and management plan.

A growing body of scientific evidence demonstrates that the psychosocial problems created or exacerbated by cancer (eg, depression and other emotional problems or a lack of information/skills needed to manage illness) can be effectively addressed by a number of services and interventions.[68-72] Data are unequivocal in showing that psychosocial interventions can improve cancer patients' quality of life.[72-83] The intensity of intervention mimics the paradigm presented in the World Health Organization's pain ladder.[35,84-86] The most basic level of intervention is the provision of psychoeducation about the disease, treatment, and prognosis. The next level includes interventions provided by specialists such as psychologists, social workers, psychiatrists, and psychosocial oncologists. The highest level of intervention is the provision of services by psychosocial oncologists in combination with pharmacologic intervention.

Drawing from other disciplines and using techniques and strategies that create change in patients and their families, physicians can navigate this difficult process. Motivational interviewing (MI), solution-focused brief therapy (SFBT), and cognitive behavioral therapy (CBT) are empirically validated methods of therapy that can be taught to residents during their training. Incorporating MI aspects of existential therapy, metaphors, and storytelling in the processes of delivering bad news and medical decisionmaking can diminish distress for all parties. Some basic tenets of therapeutic communication can help to facilitate patient narratives. Examples include avoiding close-ended questions and asking for "the story" in a patient's own words.

MI and CBT are validated methods of therapy that can help patients with diseases such as diabetes and asthma overcome their resistance to acknowledging difficult truths about their diagnoses and inimical health behaviors.[87-94] A Cochrane review indicates that MI may be beneficial in changing behaviors.[95] A common aspect of MI and CBT is the fundamental acceptance and utilization of distress, including resistance and denial, that promote the acceptance of the offered therapeutic intervention.[75] Rather than confronting the resistance generally inherent in an individual's will to live, these therapies use it to alleviate the patient's discomfort. The patient's distress can be used to improve his or her status or at least to change perceptions, attitudes, and behaviors.[96]

The combination of SFBT and MI techniques is uniquely suited to address the struggle clinicians may have in supporting patient autonomy when they disagree with a patient's choices. Specifically, MI techniques such as reflective statements and summarizing can help reduce a patient's resistance, resolve patient ambivalence, and support patient autonomy. Not all MI techniques are applicable, however, in part because palliative care clinicians do not guide patients to make particular choices but instead help patients make choices consistent with patient values. Some elements from MI and SFBT can be used to improve the quality and efficacy of palliative care conversations.[97]

Using the miracle question,[98-100] an SFBT technique, can prompt a moment of clarity when a patient realizes that the only way that the disease would reverse direction would entail a miracle. The essence of the miracle question removes the onus of the clinical direction from the health practitioner and allows a patient and family to set treatment goals. The miracle question can be framed in many ways. It is often as simple as asking a patient to speculate about these questions: "If a miracle happened during the night and *XYZ* (freedom from discomfort/open communications/conflict resolution) were to be resolved, what would that look like? What would be different?" The miracle question can provide clearly defined objective treatment goals and a vehicle to align treatment goals of all concerned.

CONCLUSION

Palliative care relies heavily on communication. There is a clinical imperative to educate physicians and other healthcare workers on how to effectively deliver information about a patient's health status, diagnostic avenues to be explored, and decisions to be made at critical health junctions. These difficult conversations are crucial throughout the treatment trajectory. Knowing how to implement the most

rudimentary techniques of MI, SFBT, and CBT can help physicians facilitate conversations of the most difficult type to generate positive change in patients and families and to help them make decisions that minimize end-of-life distress.

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This article meets the Accreditation Council for Graduate Medical Education and the American Board of Medical Specialties Maintenance of Certification competencies for Patient Care, Medical Knowledge, and Interpersonal and Communication Skills.