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Current State of the Art and Science of Patient-Clinician Communication in Progressive Disease: Patients' Need to Know and Need to Feel Known

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Effective communication rests at the core of medicine, especially when patients are confronted with progressive disease and death. Communication can mitigate the distress of receiving bad news and influence patients' psychological functioning and adaptation to a new situation.¹⁻³ Whereas the benefits of good communication might seem clear, the costs of its failure are perhaps even clearer. Especially in progressive disease (which we define as entailing palliative and end-of-life care in worsening serious illness) with guarded prognoses and significant psychosocial stressors, the stakes are high in most if not every clinical encounter with patients and families. Communication deficits cause unnecessary distress not only for patients but also their loved ones.⁴ It is not surprising that most formal complaints in health care are believed to be related to communication.^{5,6} Herein, we therefore tackle the central question that remains: what is good, effective communication in progressive disease and how can it be taught, evaluated, and implemented to improve patient outcomes? In medical consultations, patients experience a double-need: *to know and understand* and *to feel known and understood*.⁷⁻⁹ These simultaneously present needs can be roughly seen as a need for information and for empathy. The need to know can be satisfied by explanations of test results, treatment options, or prognosis. The need to feel known can be satisfied by both verbal (eg, reassurance) and nonverbal (eg, eye contact) empathic behavior.

Data speak to the importance of empathy (or synonyms such as caring¹⁰ or compassion¹¹) on patient outcomes. Receiving empathic communication is of the utmost importance for patients confronted with a (potentially) life-limiting diagnosis.^{3,12-15} Even empathic remarks of 30 to 40 seconds (eg, expressing reassurance about nonabandonment) can positively influence patient evaluations of consultations wherein bad news was delivered.^{16,17}

In a series of articles, Back et al have, after delineating the importance of empathy for patients,¹⁸⁻²⁰ recently taken this one step further by describing ways to make the connection between the patient's emotional and rational mind,²¹ uniting the dual needs to know and feel known. According to them, a preoccupation with empathic responses can decrease attention for cognitive needs, thereby hindering a sometimes necessary transition from empathy to action. The opposite situation (sole information provision that overlooks responding to emotion) also occurs,²² leading to suboptimal outcomes, such as impaired recall.^{23,24} This underlines the importance—despite its



difficulty²¹—of linking and responding to patients' cognitive and emotional needs simultaneously.

To achieve this, we propose that communication skills should be taught within a framework that entails approaches for both cognitive and emotional data, which patients and families present clinicians with daily. Two models fit this framework well and, when integrated, have the potential to meet patients' double need. SPIKES²⁵ proposes six steps in delivering any bad news with empathy: setting up the encounter; assessing patients' perceptions; querying informational receipt style/obtaining invitation to share the news; delivering the news (knowledge); exploring emotions with empathy; strategizing/summarizing next steps.²⁵ Although the *E* is for empathy, embedding an additional and empathy-specific model, NURSE (name the emotion, express statements of understanding, respect, and support; and explore emotion)²⁶⁻²⁸ might help to integrate empathy in information provision. Although the two models are not new, by combining them, clinicians can maximally address, simultaneously, the cognitive and emotional needs of patients.²⁹ If physicians solely use SPIKES in challenging consultations, concrete steps and examples on navigating empathy are often missing, despite it being perceived as the most challenging step.²⁵ If solely NURSE is used, the focus could be too much on empathy, eliciting fewer positive responses than a combined empathy/information-provision focus.³⁰ This integrated framework can help clinicians switch from empathy to summarizing and discussing future strategies, as Back et al²¹ advise. Table 1 links the theoretical model of patients' need to know and need to feel known to concrete examples of a combined SPIKES/NURSE model, which can help clinicians navigate challenging consultations. In an increasingly complex medical world, we believe this model can be used in challenging situations that encompass critically important discussions such as illness recurrence and re-evaluating goals of care among others. It can serve as a useful addition to current communication trainings, which seem varied,^{33,34} and sometimes seem to teach information-provision and empathy as distinct building blocks (eg, Oncotalk via www.oncotalk.info/). Lastly, the use of communication mnemonics fits into the emphasis on mnemonics in medical teaching and practice and might ease its recall.

[TABLE 1.]

When proposing this framework for teaching medical communication, it is important to note the recent challenges to the notion that training communication skills and frameworks improve patients' outcomes. Despite literature that the use of communication skills increases after learning them,³⁵⁻³⁷ a recent Cochrane review concluded that there is little evidence that communication trainings in oncology improve patient outcomes.³⁸ A recent randomized controlled trial (RCT) found that teaching communication skills (including the SPIKES model and a focus on empathic responses) did not increase patients' evaluations of quality of communication or quality of end-of-life care,³⁹ although a similar study in oncology suggested positive effects on patient depression amid other nonsignificant outcomes.⁴⁰ Other studies have found that, among patients receiving palliative chemotherapy, those who were more aware of the incurability of their disease reported lower scores on physician quality of communication⁴¹ and lower overall quality of life and psychosocial functioning.⁴²



Instead of taking these overall results as indicative that communication trainings, and challenging discussions might need to be avoided, a more plausible conclusion seems that teaching clinicians communication skills leads to more honest discussions, which will inevitably evoke emotional distress. It would then be hasty to eliminate communication trainings, given that patients expect oncologists to be honest with them.^{14,43,44} The crux seems to be striking a balance between communicating the reality of the situation to patients with progressive illness, all the while maximizing empathic responses when these emotions come to the fore. This is where empathy alongside information provision becomes critical, including the need to teach and practice both sides of the communication coin.

At the same time, building the evidence for the effect of communication elements and trainings by conducting high-quality studies—especially RCTs—in progressive disease is needed but presents challenges as well. Such studies are almost always complex interventions with inherent challenges including threats to standardization and contamination and requiring large sample sizes to account for clustering at the clinician and institution levels. Other difficulties include a lack of research funding,⁴⁵ difficulties obtaining ethical approval, gate-keeping by clinicians for patient recruitment, high anticipated patient dropout, choosing the right end points, and a reliance on proxy reports.⁴⁶

Although acknowledging these and other limitations, we propose key (albeit nonexhaustive) improvements in the composition and evaluation of communication trainings and studies (additional recommendations on this end-of-life research arena can be found elsewhere⁴⁶). First, for trainings to have a true impact, it might be necessary that patients and family caregivers are involved in their creation and delivery. There would be feasibility and ethical issues to consider when applying this approach (eg, careful selection and preparation of patients/families would be essential), but successful examples have been described in the literature.⁴⁷ The aforementioned RCT showing some positive effects on patient outcomes indeed used the patient perspective literature to build their communication training.⁴⁰ Moreover, early patient involvement is increasingly a focal point of research funding bodies (eg, the Patient-Centered Outcomes Research Institute⁴⁸ in the United States and the National Institute for Health Research⁴⁹ or the Medical Research Council⁵⁰ in the United Kingdom) and might ease obtaining ethical approval.⁴⁶ It might also increase incorporation of the true patient perspective in trainings, increase clinicians' involvement (opposed to working with simulated patients) and improve patient outcomes. In the end, communication is as effective as the influence it has on patients' perceptions.

This makes patient-reported outcomes among the important outcomes to study; however, the trial by Curtis et al³⁹ suggests that these outcomes are complicated. Coming to terms with an incurable diagnosis inevitably makes people sad, whether or not the information has been provided in an empathic and comprehensive manner. Outcomes might, however, be worse when patients are aware of their situation without having received empathic communication or the chance to discuss their situation with their medical team. There is evidence that patients accepting a terminal prognosis feel less depressed, anxious, or hopeless than nonaccepting patients.⁵¹ The recent evidence base demonstrating the beneficial effects of palliative care interventions⁵²⁻⁵⁵ and end-of-life discussions^{56,57} also indirectly supports this notion.



In addition, outcome measures would ideally be collected at several time points, to determine direct and indirect effect of communication trainings. Because more downstream outcomes (eg, quality of life) are influenced by many other factors than communication, longitudinal studies could examine the effect of communication within the context of other (confounding/mediating/moderating) variables. The idea of pathways in which communication influences subsequent variables and outcomes has been proposed^{58,59} and also takes into account the reality of context when building the evidence base of communication. Notorious challenges for such longitudinal model-driven studies are the need for a large sample size and an expert research team to deliver and analyze this complex intervention. However, recent studies (eg, the studies by Prigerson et al⁵⁷ and Temel et al⁵²) have shown that this is feasible and can influence care and policy recommendations.⁶⁰

Lastly, to achieve implementation of evidence-based interventions and findings, we believe several investments should be considered. Standardizing and disseminating mandated communication training would be a significant but promising undertaking that has increasingly been supported^{34,61,62} and fits the notion that a lack of training hampers effective communication.^{63,64} Such initiatives would also be in line with core competencies and associated milestones set forth by national educational bodies, such as the US Accreditation Council for Graduate Medical Education and the American Board of Internal Medicine.⁶⁵ Mandated trainings would address the current problem of the self-selection of participants that hampers broad implementation and demonstration of training effects. With the growing evidence base regarding the effect of communication, we believe such trainings need to be considered beyond medical school for established physicians as modules of continuing medical education credits.

In addition, although effective communication is not always time-consuming (eg, ^{16,17,23}), we do appreciate the time commitment these sensitive conversations often entail and plea for providing clinicians with sufficient time for doing this. Next to improving patient outcomes (eg, ^{52,55}), recent literature has documented the resource-saving nature of palliative care consultations,⁶⁶⁻⁶⁸ of which communication is a major part. It is promising to see a renewed US push for reimbursement of discussing patients' advanced treatment preferences.⁶⁹ A third investment, in line with the trend of specialist versus generalist palliative care,⁷⁰ is the former sharing their expertise with the latter group, which is likely to improve dissemination of knowledge. Lastly, the increase in interactive dissemination (eg, the Center to Advance Palliative Care's *getpalliativecare* initiative) and learning tools via Internet (eg, www.vitaltalk.org) likely will enhance dissemination of communication skills. In conclusion, good communication will always rest at the heart of medicine, serving the patients' needs for both information and empathy. As the recognition of empathy as a core clinical skill grows, we propose a theory-based framework integrating SPIKES and NURSE to serve patients' double needs in progressive disease and challenging situations. Although indirect support exists for this approach, more evidence is needed regarding its effect on patient outcomes. Conducting sound research in this arena is difficult but might be achieved by involving patients/families in the development of communication courses, by measuring optimal patient-reported outcomes in longitudinal studies run by expert teams, and by working within the real world, in which outcomes are influenced by numerous other variables. New knowledge should be implemented in clinical care by mandating



communication trainings, allowing time for communication, transferring knowledge from experts to generalists, and through interactive dissemination. Serious illness and death are challenging for all involved. Further examination and improvement in the way we train current and future clinicians to help patients and families navigate these choppy waters is therefore essential.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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TABLE



Table 1. Patients' Need to Know and to Feel Known: An integrated SPIKES Model of Breaking Bad News* and NURSE† Model of Empathy Expression

Component	Need to Know	Need to Feel Known
SPIKES/NURSE		
Setting	Analyze key <i>medical</i> information (pre-meeting) and discuss it, if needed, with other medical providers who have been involved in the patient's care. Invite key family and interdisciplinary medical team players (pre-meeting). Arrange proper physical setting (quiet, private room with adequate seating, tissues, and water). At meeting start, address the agenda/meeting goals.	Analyze key <i>personal</i> information (pre-meeting) and discuss it, if needed, with other medical providers who have been involved in the patient's care. At meeting start, sit down and make introductions.
Patient perception/perspective	"I have already reviewed all of the medical information, but please tell me what the doctors have already told you about what's going on." "What is your understanding of the current medical situation?"	"I know all the medical details, but tell me more about who you were before this illness and how this has affected you and your loved ones."
Invitation/information	"Would it be okay if I shared the medical information with you?" "Some people prefer very detailed information, others prefer to hear only the rough picture, and then there are those in the middle. What kind of person are you?"	
Knowledge	If appropriate, fire warning shot eg, "I'm afraid I have some bad news." or "Unfortunately the tests did not reveal what we hoped they would." Avoid medical jargon or too much all at once, check in frequently, and speak clearly but sensitively. "Given what's happened medically and what your perspectives and goals are, I would recommend . . ."	Recognize the difficult nature of receiving bad news, use silence after breaking bad news.
Empathize/explore emotions		
Empathy/NURSE†		
Name emotion		"You seem very upset by the news."
Understand		"You seem quiet. Can you tell me what you are feeling?" "I can't imagine how difficult this news must be for you." "Your reaction to news like this is completely natural."
Respect		"You've done such a good job of coping thus far with the situation." "You've shown a lot of courage in talking about/coming to grips with the situation."
Support		"I wish things were different." "No matter what happens, we are going to be here to support you and your family through this."
Explore emotion		"We've just discussed a lot. Tell me more about what you are feeling right now." "What are your most pressing concerns?"
Strategize/summarize	"What questions do you have?" Reiterate availability of team to field additional questions/concerns. Summarize the next steps and appointments. Ensure appropriate follow-up and delivery of contact information.	
<p>NOTE. The concrete examples provided are meant to be neither exhaustive nor prescriptive but can serve as useful guides for both clinical practice and teaching. All components need not be used in one conversation, nor should they always proceed in this order. In particular, empathizing may be necessary more than once and at any time during an encounter. Finally, these steps are often best used as part of an ongoing relationship-building process instead of a one-time event. Interested readers might also benefit from the work of Baile et al,²⁵ Pollak et al,²⁸ Back et al,²⁷ Saraiya et al,³¹ and Campbell et al³² for examples on the SPIKES and NURSE methods.</p> <p>*Adapted from Baile et al.²⁵</p> <p>†Adapted from Pollak et al.²⁸ and Back et al.²⁷</p>		