REVIEW

Delivering Bad News in Amyotrophic Lateral Sclerosis

Proposal of Specific Technique ALS ALLOW

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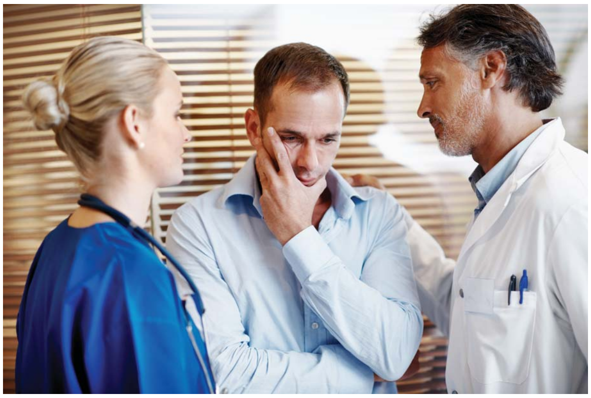
Neurology: Clinical Practice December 2021 vol. 11 no. 6 521-526 doi:10.1212/CPJ.0000000000000957



Abstract

Purpose of Review

Physician communication skills are a critical part of care for amyotrophic lateral sclerosis (ALS) patients and caregivers. They shape the development of autonomy and quality of life, and they mitigate emotional trauma. Communication skills are especially critical at 2 different time points in the course of the disease: early when delivering and establishing the diagnosis, and later when clarifying goals of care.

Recent Findings

Several techniques for physician communication of difficult information are available, including SPIKES (Setting up the interview, assessing the patient's Perception, obtaining the patient's Invitation, giving Knowledge and information to the patient, addressing the patient's Emotions with Empathetic responses, and Strategy and Summary), ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions), and BREAKS (Background, Rapport, Exploring, Announce, Kindling, Summarize). These emphasize the physician's accountability and responsibility for communicating effectively. Formal training in these techniques is limited, and their applicability specifically to ALS is inexact.

Summary

We propose an ALS-specific technique which we call ALS ALLOW to guide physicians in conducting difficult communications with ALS patients and caregivers to develop their understanding, establish autonomy, set goals, and mitigate emotional trauma. The techniques are useful in discussions both early and late stages in the disease.

Defining Bad News

Bad news has been medically defined as "unfavorable information that adversely and seriously affects an individual's view of his or her future."[1] Conveying bad news to patients is an arduous and emotionally challenging task for which experience and education go hand-in-hand.[2–5] Many physicians feel that they are not well prepared for this task and medical curricula devoted to this are limited.[6–10]

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Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

Importance of Delivering bad News Effectively

Effective physician communication has been shown to help patients understand their disease process and treatment options, which subsequently improves patient communication of needs, future planning, sense of control, pain tolerance, and daily functioning.[11–13] Studies that investigate the importance of physician delivery of bad news have been performed in various patient populations, ranging from healthy volunteers (i.e., analog patients) to patients in oncology, neurology, general medicine, and traumatic injuries.[2,14–19] Physicians with good interpersonal skills and compassionate communication are clearly important.[20,21] In both diagnostic and prognostic scenarios, patients reported better recall, reduced stress, and more hopefulness when communicating with physicians who employed robust communication techniques. Warning statements, empathic statements, and "positive" framing of future healthcare outcomes were especially effective.[22] Patients report increased quality of life when physicians have good communication and when patients feel that they are given decisional control over how they would like to proceed with their care.[23–26]

Challenges of Conveying Bad News

A patient's perception of "bad news" is personal and highly variable. The burden falls to the physician to identify the effect of such news and accordingly tailor its delivery. While this may seem easy in theory, when the moment arrives, it may be very difficult to adequately convey the gravity of the news, while simultaneously addressing the associated psychosocial ramifications.[14,27] This is an even greater hardship for inexperienced physicians (e.g., interns, residents), particularly when there is a poor prognosis or little therapeutic hope.[15,28,29] Patients typically want to know their diagnosis and to discuss treatment options, therapy side effects, and likelihood for a cure.[30] Barriers to an effective physician communication include gravity of conversation, patient preparedness, individual personality, cultural and language differences, physician's own emotion, lack of time in productivity-driven healthcare systems,[31–33] and inexperience. Some patients desire to know the bad news in one setting, while others prefer to receive piece-meal information and most patients wanted their doctors to address their emotional needs in the same setting of receiving their bad news.[34]

Physicians and trainees report feeling fear and/or psychological distress that negatively affects their own well-being and their ability to provide high-quality care in disclosing bad news.[35–37] Moreover, a physician may be reluctant to deliver bad news given associated feelings of anxiety and fear of ensuing patient response, a phenomenon that psychologists have termed the "mum effect."[38] The mum effect can lead to a delay in diagnosis and follow-up care while delivery of the bad news is avoided.

It is thus imperative that physicians become better trained in the task of delivering bad news, that it becomes a skill, and that standards of care ensure good communication and optimal information to every patient.

Bad News Delivery Techniques

A number of techniques have been developed to assist physicians with delivering bad news more easily and effectively (Table 1). These techniques incorporate many of the variables identified by patients and caregivers based on surveys. Although all typically share common principles, each has its own unique emphasis. The SPIKES (Setting up the interview, assessing the patient's Perception, obtaining the patient's Invitation, giving Knowledge and information to the patient, addressing the patient's Emotions with Empathetic responses, and Strategy and Summary) technique was developed to enable physicians to deliver bad news about cancer in a patient-centered manner by addressing concerns about patient care and long-term outcomes.[13,30,39–41] The ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions) protocol addresses the steps in the SPIKES technique, while additionally taking into account the feelings of the physician.[42] The BREAKS (Background, Rapport, Exploring, Announce, Kindling, Summarize) protocol outlines a strategy similar to SPIKES but highlights the importance of understanding a patient's cultural and ethnic background.[43]

Challenges for Amyotrophic Lateral Sclerosis Patients and Their Caregivers

The majority of literature examining the effects of patient-physician communication of bad news has focused on oncologic diagnoses, which often have substantial treatments and often cure.[44–46] This is fundamentally different from amyotrophic lateral sclerosis (ALS), which remains progressive and fatal usually from respiratory insufficiency in essentially all cases even despite extensive biomedical research, new medications, and availability of clinical trials.[47–53] Furthermore, ALS patients often receive bad news at 2 different stages of the disease. Early in the disease, they typically learn of their diagnosis when they are highly functional. They may even initially self-diagnose after long internet searches. Ineffective communication at this early stage may cause emotional trauma, and the patient's quality of life may be compromised by posttraumatic stress disorder. Then, later in the disease, after a variable period of time usually ranging between 1 and 3 years, they must formally reckon with prognosis, and these discussions involve respiratory failure, goals of care, palliation, dying, and advanced directives. Ineffective communication in this stage may cause unrealistic expectations, unpreparedness, and respiratory crises. All of this is further complicated by the fact that the disease manifestations of ALS are markedly heterogeneous. The onset of muscle weakness can occur in variable regions including the limbs, bulbar, truncal, or respiratory muscles. Motor manifestations can be of upper or lower motor neuron character. Higher cortical functions including affect and executive functions can also be affected.

Table 1 Techniques for Breaking Bad News

SPIKES[30]		ABCDE[42]		BREAKS[43]	
Setting	Create a setting in which the physician can ensure privacy and establish a connection with the patient and anyone else the patient chooses to bring with them.	Advance preparation	Prepare for the discussion, both logistically and emotionally.	Background	Understand not only the background of the diagnosis you will convey, but also the background of the patient.
Perceptions	Get a sense of what the patient knows by using open-ended questions like "what do you know about 'X' disease?"	Build a therapeutic relationship	Inform relevant staff and colleagues of the situation. Identify how the patient would like to receive the news.	Rapport-building	Build a good rapport with the patient by avoiding patronizing or hurried attitudes.
Invitation	Invite the patient to tell you how they would like to be informed of the news.	Communicate well	Communicate the results clearly, understanding that the patient may not hear everything you say.	Explore patient knowledge	Explore what the patient and their family know about the illness, and what effects the diagnosis can have.
Knowledge	Warn the patient that you are giving them bad news with phrases like "I am very sorry to tell you this." Then, proceed with explaining the situation using simple language, instead of complex medical jargon.	Deal with the patient	Deal with patient and family reactions by showing empathy and being attuned to body language.	Announce	Announce the diagnosis after getting consent. Do this clearly, and do not give more than 3 pieces of information at time.
Empathy	Identify the patient's emotional response in order to adequately empathize with them. Give validating responses to the patient's statements.	Encourage emotions	Validate emotions, offering realistic hope based on the patient's overall goals.	Kindle	Kindle emotions, while ensuring that the patient understands what you are telling them.
Strategy and summary	Explore treatment options and concisely review information provided in the visit.			Summarize	Explain the points discussed in the patient interview and ensure follow-up.

Disease progression can be slow or rapid. It is often challenging even for experienced ALS neurologists to predict a timeline for patient prognosis. In addition, there is an abundance of information on the internet about ALS, some of it distressing and some misleading, but it is important to lay out a framework with which to educate and enhance patient understanding.

The SPIKES technique has been studied in ALS.[54] Expressing empathy and emotional support, giving information and time to process information, and discussing next steps including multidisciplinary and palliative care were important. Although the SPIKES technique has thus been shown to have efficacy, there are parts of the protocol that can be specifically tailored to ALS patients to better meeting their needs.

ALS-Specific Recommendations

Here, we propose a protocol, ALS ALLOW, modified from existing protocols in an effort to directly address the unique communication challenges of ALS, both early and late in the disease course (Table 2).

Step 1: Ascertain

At the beginning of the discussion, the physician needs to ascertain start-points. They do this by asking the patients and also their caregivers their thoughts, opinions, and beliefs. Thus, the physician's delivery and discussion can be tailored to the exact start-points of participants; many difficult discussions can be avoided if start-points are correct. Early in the disease when delivering the diagnosis, ask what they think might be wrong and what they have been told. Later in the disease when the conversation is about prognosis and goals of care, ask where they think they are heading, if they looked ahead and what they think about these.

Step 2: Leave Opportunity

Begin discussion gradually leaving ample opportunity for interaction—the physician must rapidly adapt and direct the discussion to the immediate audience.

Step 3: Stratify

Present information in a step-down approach that allows the patient and their caregivers to understand the information without becoming overwhelmed. Although patient and caregiver thoughts, questions, and emotions may be unfiltered and uncontrolled, it is the role of the physician to organize and prioritize and stratify discussion. Assimilating information is a process that occurs *over time*, and it is easy to become tangential. Furthermore, explaining the best sources of information, including verified and peer-reviewed websites, may be helpful.

Step 4: Anchor

Both early and late in the disease course, too much or too little information is problematic, and the physician must anchor it. Early in delivering the diagnosis, too much information may be

Table 2 Proposed ALS-Specific Guidelines for Breaking Bad News: ALS ALLOW

Step		Process	Comment
1	Ascertain	At the start of the appointment, the physician should first ascertain participants' perceptions	Start from the patient's and caregiver's self-assessment and start-points.
2	Leave opportunity	As the discussion proceeds, allow ample opportunity for interaction.	Physician needs to assess patient response and rapidly adapt.
3	Stratify	Stratify information, information to be assimilated at an individual rate, which may take weeks, months, or even years.	The physician needs to provide step-down information and prioritize and pace content.
4	Anchor	Allow the patient to control and "pull" information and not mechanically "push" unless deemed necessary.	The physician should balance the need to know with right to know, to allow applicability of information and readiness.
5	Let it be	Recognize and accept highly variable patient responses such as denial—patient autonomy develops over time.	Patient's understanding of ALS is an evolving process.
6	Listen in silence	If emotions become strong or volatile, remain silent and allow waves of emotion to subside.	Physician silence is a productive and powerful tool. Occasionally, a recess is helpful.
7	Offer over time	Often, attention fatigues after 30 or 60 min, and discussion becomes inefficient or nonproductive.	Plan on follow-up appointments with recurrent discussions.
8	Work together	Schedule follow-up care into an appropriate format, either individual clinic or multidisciplinary clinic. Second or even third opinions are often helpful, even for referral centers.	The physician should individualize follow-up visits. ALS multidisciplinary care programs are effective for patients who are emotionally ready, and individual clinic follow-ups are best for patients who are not.

Abbreviation: ALS = amyotrophic lateral sclerosis.

overwhelming, premature, or unnecessary, but too little information may be frustrating, misleading, and leave them unprepared. Later in the disease, too little discussion about goals of care and advanced directive leaves patients and caregivers unprepared and leads to crises.

Step 5: Let It Be

Accommodate various responses including denial especially early in the disease. Understanding ALS is a process that evolves over time, and denial is a critical defense mechanism—pushing against it moves into an uncomfortable emotional space for little gain and may sacrifice long-term trust. "Letting it be" does not apply to denial late in the disease course when it leads to unpreparedness and crises, and at such time, the physician must press the patient to important discussions about goals.

Step 6: Listen in Silence

Physician silence is powerful and important and is not well taught in training. When patients and caregivers are overwhelmed by emotions, silence is golden and sometimes even stepping out of the room to allow privacy is helpful. Trying to communicate during surges of emotion is unproductive.

Step 7: Offer Over Time

Productive discussions need time, and single visits are fatiguing and saturating for patients, caregivers, and physicians. A single visit often becomes ineffective after 30–60 minutes, and discussions at different times need to occur.

Step 8: Work Together

ALS care is both medical and psychosocial. ALS Multidisciplinary Clinics are a critical resource. However, these may be overwhelming especially early on, and some patients and their caregivers are not ready mentally or emotionally, in which case single physician follow-up visits are the best. Late in the disease, home care or hospice may be most appropriate. The physician should individualize follow-up formats and timelines.

Conclusion and Recommendations

Effective physician delivery of bad news is essential for providing humanistic and individualized patient care for ALS. The recommendations for delivering bad news to ALS patients outlined in this paper address the unique complexity of ALS and are adapted from SPIKES, ABCDE, and BREAKS protocols that take a patient-centered approach. These recommendations apply to both delivering initial diagnosis and later discussions of goals of care and end of life. Patient autonomy is built over time on a patient-physician alliance that starts early in the disease course and evolves over time. Future discussions by the ALS and palliative care communities are required to explore complex boundaries between physician duty and patient autonomy.

Study Funding

No targeted funding reported.

TAKE-HOME POINTS

- → Physician communication with ALS patients and their caregivers has unique challenges.
- → Skillful communications are especially important at 2 different time points: early in the disease when delivering the diagnosis and later in the disease when establishing goals of care. These communications have different aims, but the skills are essentially the same.
- → One essential skill is to first establish start-points of conversations from patients and caregivers and then based on those, individualize communication, prioritize topics, and pace.
- → Physician communication is a skill that can be taught and learned.

Disclosure

The authors report no disclosures relevant to the manuscript. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

Publication History

Received by *Neurology: Clinical Practice* April 20, 2019. Accepted in final form April 24, 2020.

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