

Chapter 23

A person-centred approach to breaking bad news

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Abstract

Receiving a neurological diagnosis is typically an extraordinarily difficult time for patients and their families and has been described as a type of existential shock. Communicating the news of a serious diagnosis is a frequent yet stressful part of the work of many health professionals. In this chapter, an evidence-based resource for how to discuss difficult neurological diagnoses with patients and their families is provided. The SPIKES protocol for communicating bad news is described. Its applicability to communicating the diagnosis on motor neuron disease is then explored, with data from neurologists, patients, and their family members. A case study and real-life examples are used to illustrate the components and the complexities of best-practice communication of a neurological diagnosis. The delivery of bad news, such as communicating a serious diagnosis, is not an optional part of clinical practice; instead, it is imperative that health professionals are prepared to deliver bad news. Communicating the diagnosis in an evidence-based and person-centered manner is necessary in order to promote optimal outcomes for patients and their families, and doing so also has the added benefit of mitigating against the stress experienced by health professionals when delivering bad news.

Key words: Communication, Diagnosis, Neurology, Person-centered care, Evidence-based care, Motor neuron disease, Amyotrophic lateral sclerosis, Family caregivers

A PERSON-CENTERED APPROACH TO BREAKING BAD NEWS: WHAT CAN BE LEARNT FROM MOTOR NEURON DISEASE?

Neurodegenerative diseases are associated with increasing disability, shortened life expectancy and a host of physical, emotional, and existential problems coupled with unmet care needs starting from the time they receive the bad news of their diagnosis [1-5]. The term “breaking bad news” encompasses the communication of any information that seriously and adversely affects the receiver’s expectations of the future, quality of life, and availability of choices. Examples include the communication of a serious diagnosis and/or prognosis such as life-limiting illnesses (e.g., cancer), chronic illnesses (e.g., diabetes), neurodegenerative illnesses (e.g., amyotrophic lateral sclerosis/motor neuron disease), and genetic conditions (e.g., Down syndrome).

The del

ivery of bad news is one of the more stressful experiences of health professionals. Several studies have shown that medical and health professionals report the delivery of bad news to be a taxing experience [6, 7], yet it is a relatively new addition to their training [8, 9]. However, the delivery of bad news, such as communicating a serious neurological diagnosis to patients and their families, is not an optional part of clinical practice; instead, it is imperative that health professionals are prepared to deliver bad news. It is encouraging to know that this skill can be improved, via explicit instruction and practice of evidence-based protocols, to enhance the patient's satisfaction with care, promote their adjustment to the diagnosis and disease, and optimize their health outcomes [9-12].

The receipt of bad news is often experienced as being without respect or compassion, leaving patients and their family caregivers feeling shocked, confused, hopeless, angry, and devastated [13-16]. The rate of dissatisfaction was reported to be 56% in a survey of patients and caregivers in the United States [17] and data from Australia showed that 33% of caregivers [18] and 36% of patients were dissatisfied with the delivery of the diagnosis [19]. Some complaints about the process of receiving bad news are exemplified in **Fig. 23.1**, in which the presented scenario does not follow recommended practice standards [20] in the following aspects: the person should not be seen alone, and the consultation time was much shorter than the recommended 45-60 minutes. The delivery was not empathetic, the medical terms were not explained, no opportunity was given to respond to the patient's emotions, and it offered a false sense of hope. This bad news was delivered at the end of the week on a Friday in a locale where there were no support services operating on the weekend. Additionally, no referral was made to an appropriate disease-based support association for information and follow-up assistance.

SPIKES: A Protocol for Communicating Bad News

The SPIKES protocol was developed to provide a method for communicating a cancer diagnosis to patients. It is an acronym that outlines the six components of the protocol—Setting (creating the right setting), Perception (determining what the patient/family knows), Invitation (exploring what patient/family are expecting or hoping for), Knowledge (sharing information and suggesting realistic goals), Emotion (responding emphatically to the feelings of patient/family) and Strategy (making a plan and follow through) (Table 23.1). Not only does the protocol facilitate the receipt of a diagnosis, it also assists the health professional by providing a structured way of communicating this news [10].

Utility of the SPIKES Protocol for Communicating a Neurological Diagnosis

The communication of a specific neurological diagnosis has been comprehensively investigated from the points of view of neurologists, people with motor neuron disease (MND), and their family caregivers [18, 19, 21-23], and this chapter's focus is to illustrate the challenges of breaking bad news associated with MND. Patients' and their families' confrontation with the diagnosis of MND has been understandably described as an "existential shock" (Brown [24], p. 210) and the catalyst for "constant loss" (Aoun et al. [15], p. 845). The majority of neurologists describe the communication of the diagnosis as stressful [25]. Despite this, however, very few neurologists report having received adequate training in the effective communication of a diagnosis of MND [25].

A series of studies investigated how neurologists communicate the news of a diagnosis of MND. Questionnaires were posted to neurologists, to people living with MND, and to their family caregivers and facilitated by all MND associations in Australia. Only 6% of the neurologists surveyed ($n = 73$) reported feeling no stress when communicating the diagnosis; the remainder reported slight (29%), moderate (53%), or high (12%) stress [21]. Similarly, only 7% described the delivery of diagnosis as “not difficult,” with the rest describing it as a “little difficult” (24%), “somewhat difficult” (32%), “difficult” (28%), and “very difficult” (9%). Nearly half (44%) reported having received no training in how to respond to patients’ emotions, and, importantly, 74% expressed interest in receiving such further training. The neurologists described being challenged by the need to be honest, yet not to take away hope; by the lack of an effective treatment; by fear of causing distress, by dealing with the patient’s emotions; by spending the right amount of time; and by fear of not having all the answers.

For example, one neurologist wrote:

Having had a migraine after each MND clinic, feeling stressed and anxious about having so little to offer, I have gradually accepted the limitations of my skills, and some confidence that assisting the patients honestly and empathetically, and not ‘abandoning’ them is of value to most patients. [21, p. 370]

A survey of 248 MND patients highlighted that, 36% were dissatisfied with the way the diagnosis was communicated [19]. Further, in examining the six SPIKES domains, those neurologists whose skills and abilities were “above average” were significantly more likely to explore the domains of Invitation, Knowledge, Emotions, and Strategy than those who were “average or below”. The largest difference related to the neurologists’ abilities and skills in responding empathically to the feelings of patient/family (**Fig. 23.2**). The survey of 190 family caregivers told a similar story, in that 33% were dissatisfied with the delivery of the diagnosis, and there was the same pattern concerning differences in the SPIKES domains between neurologists they rated as “above average” and “average or below” [18].

These quantitative findings are complemented by an analysis of the responses to the open-ended questions in the questionnaire. The patients and family caregivers described difficulties and time delays in receiving the correct diagnosis, the shock and distress of being diagnosed, the importance of the neurologist’s manner and skills in delivering the diagnosis, and the importance of being linked to further information and ongoing support [22, 23] (**Fig. 23.3**).

Person-Centered Care in Communicating a Neurological Diagnosis

Person-centered care is an increasingly common philosophical approach to service delivery whereby the patient (and increasingly, their family caregivers being family members, friends or other informal caregivers) is respected, valued, and positioned to work in partnership with healthcare professionals in determining the healthcare plan. This approach to care is typically experienced positively by patients and their family caregivers [26] and tends to show reductions in symptomatology, pain, and hospitalization [27]. This approach is holistic and means that the diagnosis is delivered in a way that acknowledges the individual’s emotional, psychosocial, and spiritual needs as well as addressing their medical and practical needs.

How is person-centered care achieved when delivering bad news? The challenge of holistic care is that it requires more of the clinician’s time. Importantly for practice, studies show that

the time the neurologist took to deliver the diagnosis was associated with higher patient ratings of the neurologist's abilities and skills (**Fig. 23.4**) and with satisfaction with the delivery of the diagnosis (**Fig. 23.5**) [19, 21]. Those who were satisfied had consultation times over 40 minutes confirming why best practice standards [20] set this time at 45-60 minutes. A two-stage approach to the consultation is best practice and has been confirmed in the Australian survey, where this approach was used by 68% of the neurologists [21], and also by a study in the Netherlands that showed that the organisation of two appointments 10-14 days apart helped patients and their families cope better with receiving the diagnosis [4]. Given that 95% of patients reported receiving their diagnosis from a neurologist [19], and that guidelines specify that the diagnosis should be given by a consultant neurologist with experience and up-to-date knowledge of MND and its treatment and care [28], neurologists are a key group that must be encouraged to commit more time to communicate the diagnosis thoroughly, with the focus being on the needs of the patients and family caregivers. Neurologists would benefit from skills enhancing communication [23], managing distress, and being honest without removing hope [21] so that they experience less stress and discomfort in delivering the diagnosis. However, in a busy neurology clinic, adhering to such best practices may be challenging. In such circumstances, neurologists could be encouraged to adopt the two-stage approach to delivering the diagnosis. It is also worth noting that Australian neurologists working in dedicated multidisciplinary clinics were more able to provide the longer consultation as per best practice standards compared to those whose practice was not in multidisciplinary clinics, and in fact, the consultation time was twice as long (45 minutes compared to 23 minutes, respectively [21]).

It is imperative that health professionals are prepared to deliver bad news. There is growing evidence that these skills can be taught explicitly, both at university [29] and during residency [30, 31], in the context of cancer. Based on studies yielding comprehensive evidence from the perspective of both the givers and receivers of bad news, the need for education programs as well as the development of practice standards and protocols must be emphasized. The emphasis must be on a more person-centred approach to care for MND and other neurodegenerative conditions at this critical first step in an illness journey that may be traumatic, and where there is currently no cure [22].

Conclusion

The challenges of delivering a serious diagnosis are common to a number of life-limiting illnesses, particularly those neurodegenerative diagnoses that are progressive, disabling, and lacking in curative options. Receiving a neurological diagnosis is typically an extraordinarily difficult time for patients and their families and has been described as a type of existential shock. For health professionals, communicating the news of a serious diagnosis is a frequent yet stressful part of their work. The method and content of imparting a terminal diagnosis can significantly impact people with the disease and their families and has implications for the way they move from this traumatic news to the actions required for support throughout the illness trajectory. The way forward for best practice is to implement a more person-centered approach to caring for terminally ill people, starting from the diagnosis stage. The SPIKES protocol is an evidence-based resource for communicating bad news and has been shown to be applicable to discussing difficult neurological diagnoses with patients and their families. Communicating the diagnosis in an evidence-based and person-centered manner is necessary in order to promote optimal outcomes for patients and their families, such as reductions in symptomatology, pain and hospitalization and satisfaction with the delivery of the diagnosis.

Doing so also has the added benefit of mitigating against the stress experienced by health professionals when delivering bad news.

Figure Legends

- Fig. 23.1** Illustration of poor communication of a serious neurological diagnosis
- Fig. 23.2** MND patients' ratings of their neurologists' abilities/skills across the six SPIKES domains. (Aoun et al [19])
- Fig. 23.3** MND patients' [22] and family caregivers' [23] perspectives on receiving the diagnosis
- Fig. 23.4** Patients' and caregivers' ratings of neurologists' ability/skills and consultation duration (Aoun et al [18])
- Fig. 23.5** Patients' and caregivers' ratings of satisfaction with the delivery of the diagnosis and consultation duration (Aoun et al [18])

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Table 23.1 The six steps of the SPIKES protocol for breaking bad news. (Source Baile et al 2002 [10])

Steps	Guidelines	Examples
1. Setting	Setting up the interview might involve mental rehearsal of the planned conversation. It also involves attention to the physical setting of the interaction: <ul style="list-style-type: none"> • arranging privacy • involving the patient's family and friends • being seated • making a connection with the patient (i.e., rapport and micro skills of listening) • managing time and limiting interruptions. 	Try to deliver the news in a private room; if this is not an option, draw curtains around the patient's bed. Use eye contact. Sit down to show you will take the necessary time. Let the patient know how much time you have and ensure phones/pagers are on silent
2. Perception	Determine what the patient already knows/suspects, which allows you to correct any misunderstandings and to tailor the delivery of the information to the patient's level of understanding	Use open-ended questions e.g., "Why do you think we did the test?" or "What do you know about your symptoms so far?"
3. Invitation	Obtain the patient's invitation about how much information they would like to receive.	Use questions like "Would you like to have all the information about your test results?" Offer to provide further information in the future.
4. Knowledge	Foreshadow the receipt of bad news. Tailor the communication to the patient's vocabulary and comprehension. Use non-technical words and avoid being blunt. Check to make sure the patient has understood the information being communicated.	Use phrases like "Unfortunately I've some bad news to share with you."
5. Emotions	Recognize the patient's emotions and empathize with and validate them.	Example phrases include "I can see this is upsetting to you" and "I can tell this news was not what you expected."
6. Strategy	Outline a plan for the future and provide a summary of the discussion.	Ask, "Would you like to discuss the next steps in terms of treatment?" Outline options and promote shared decision-making.