4 Discussing Difficult News: Reframing Patient and Family Preferences Surrounding the Content and Style of Communication

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4.1 Scope of the Issue

Uncomfortable conversations transcend medicine across all sites of care and at all stages of a serious illness. From discussion of prognosis or prognostic uncertainty, to evaluation of competing treatment options, to disclosure of medical errors, to consideration of potentially toxic treatments, clinicians must approach such conversations with sensitivity to a patient's cognitive, emotional, spiritual, and cultural needs. Conversations small and large may be seen as "difficult" by a patient or their family, and there may be discordant views of the perceived "difficulty" of a

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C. Banerjee (ed.), *Understanding End of Life Practices: Perspectives on Communication, Religion and Culture*, Cancer Treatment and Research 187,
https://doi.org/10.1007/978-3-031-29923-0_4

conversation from the perspective of the medical team as compared to the patient or family.

Historically, the skillset involved in discussion of these types of issues has been termed "breaking bad news." Anthony Back and colleagues, in their seminal text "Mastering Communication with Seriously Ill Patients [1]," argue that in light of the increasing availability of medical information to the public, earlier diagnosis and intervention for serious illness, and an ongoing cultural transition towards shared decision-making in medicine, "talking about serious news" is a more appropriate term to define the task at hand, especially as it encourages a focus on adjusting to a new "functional and experimental normal," rather than a one-way transmission of what the authors term "brokenness [1]." In sum, news should be defined as "difficult" not only based on what the medical team deems to be serious or "bad," but also based on the cultural, spiritual, familial, and values-based concerns of a patient or family. All communication has the potential to be difficult for a patient or family to receive. Recognizing this challenge presents an opportunity for all high-stakes communication encounters to strengthen the clinician-patient relationship, build trust, deepen therapeutic presence, and encourage partnership along the journey of a serious illness.

In this chapter, we will review the core principles of transmitting difficult prognostic or diagnostic information to a patient, using well-known and validated communication paradigms as a guide. We will then discuss examples of discordance between perceived "difficult news" by the medical team and the patient or family, using a framework of curiosity and respect for diverse patient perspectives. Finally, we will propose actionable steps towards further improving communication surrounding disclosure of serious news, with an eye towards approaching every interaction as an opportunity to not only share information, but strengthen the clinician-patient bond in a patient- and family-centered manner.

4.2 Established Protocols for Discussing Difficult News

There are multiple protocols in the literature focused on providing a roadmap for discussing difficult news with a patient, each with the purpose of providing a conceptual framework to guide clinicians during the clinical encounter. Despite each model taking a slightly different approach, there are commonalities between models that are useful to highlight. Since every discussion surrounding serious news is unique, it is important for clinicians to be facile with different models and having intuitive understanding of common themes. This allows for communication that is fluid, yet anchored in key concepts.

Baile and colleagues published the *SPIKES* framework in 2000, initially targeted at oncologists faced with communicating difficult news, though the model can be used more broadly across all care settings. The model focuses on ***S****etting Up* (preparation of space and clinical preparation for the encounter); assessing a patient's current ***P****erception* of the medical situation; requesting an ***I****nvitation* to

discuss the news; sharing ***K****nowledge* by discussing the news specifically; expecting and receiving patient ***E****motion* with empathy and compassion; and transitioning to ***S****trategy* and ***S****ummary* in discussing a path forward [2]. More broadly, this model—and others like it—focus on preparation as a primary and essential tool, *prior to* initiation of the conversation, and proceeds to encourage clinicians to respond empathically to emotions, deliver news in a clear, patient-centered fashion, and allow time for synthesis and discussion of next steps.

There are several models that utilize a similar conceptual framework, with focus on the pre-work of understanding the clinical background and speaking with relevant specialists, setting up the physical (or in the case of telehealth, virtual) encounter space, effective and represents a different skillset, of news in layperson's terms, and openness to mediating strong emotional responses [3, 4]. Though understanding a patient's values is not explicitly included in the aforementioned models, the Serious Illness Conversation Guide [5] includes a reminder to explore key topics, such as fears, worries, tradeoffs, critical abilities, and sources of strength, allowing the clinician to align treatment plans with a patient's preferences.

4.3 Difficult News is in the Eye of the Beholder: Discordance Between Clinical Teams and Patients and Families

It is important to note that a diversity of "news items" shared in a clinical encounter may be perceived as difficult to hear by a patient or family member of a patient—even if thought to be innocuous to the clinician. Similarly, the medical team may worry about news being perceived as serious or upsetting, only to find that the patient and family have an unexpected emotional reaction. For example, sharing a new diagnosis of recurrent cancer may provide reassurance or relief to the patient with long-unexplained and difficult to treat bloating and nausea that has been either dismissed by the medical team or gone without diagnosis for a long period of time, despite its impact on prognosis. Conversely, seemingly "good" news might be perceived differently by a patient with values, cultural norms, life experiences, and fears that are discordant from those of the medical team. For this reason, the principles of effective communication of difficult news are important to keep in mind in every clinical encounter, particularly in the setting of serious illness.

This has been demonstrated clearly in the cancer literature. In one study, Back and colleagues performed structured interviews with patients living with gastrointestinal cancer, asking them to react in real-time to an audio recording of a physician breaking difficult news about cancer recurrence. The authors found that respondents valued when clinicians recognized the emotional impact of sharing this news, even after the news has been shared. Importantly, participants noted how important it is for clinicians to not empirically frame news in a particular negative emotional light, such as "horrible," and instead preferred a more neutral approach that allows the patient's emotional reaction to drive the discussion [6]. The authors go on to note that a clinician's ability to be responsive to a patient's

perceived emotional state—in other words, to be willing to flex and address emotions and concerns before, during, and after a piece of news is shared—promotes an encounter that is therapeutic as well as informative.

One can imagine a situation when a clinician perceives news in a profoundly different way from a patient, and how this discordance might detract from the goal of aligning with a patient along their journey with serious illness. A patient, for example, who receives news that she needs a heart transplant after a protracted course of non-ischemic cardiomyopathy causing heart failure may be relieved that a definitive path forward is available, despite their fears of surgery and the uncertainty of awaiting a donor organ. In this situation, comments from the treating team overstating the perceived "difficulty" of this news might serve as counterproductive, as they distance the clinician from the patient's perspective. A better approach would ensure consistent attention to a patient's emotional state, their non-verbal communication patterns, and the text (and subtext) of their responses. Such an approach allows the clinician to respond to the patient's emotional state, rather than impose a preconceived notion of the "seriousness" of the news.

Across multiple cultural and ethnic groups, there is a diversity of clinical scenarios that might be perceived as difficult, highlighting the importance of being constantly attuned to potential difficult news in any clinical scenario. A recent study surveyed a sample of older adults (English and Spanish speaking and reflecting a broad range of cultural backgrounds) asked participants to recall medical decisions that they perceived to be difficult, serious, or important. Across multiple genders, ethnicities, and languages, participants reported finding discussions about cancer treatment or management of medical crises to be difficult. Importantly, they also described decisions surrounding management of chronic medical conditions, medication adherence, transitions of care, and decisions surrounding both emergent and elective surgery, to be difficult or serious [7]. In other words, there was a diversity of clinical topics and decisions that were deemed serious, though not all related to traditional definitions of "bad news." For this reason, clinicians must cultivate their sensitivity to patients' and families' responses to even seemingly innocuous clinical updates, and be ready to respond to emotion.

4.4 Patients, Families, and Providers Have Differing Preferences Surrounding Discussing Difficult News

Just as it is important to recognize that patients, families, and the medical team may have discordant views on what constitutes "difficult news," it is also crucial to recognize that there is a diversity of cultural and familial norms surrounding disclosure of serious diagnostic or prognostic information. Sensitivity to these differences and a curiosity surrounding a patient's cultural or familial preferences when discussing serious news is critical to maintaining therapeutic presence.

Cultural norms surrounding discissions of difficult news are nuanced, and there is no one-size-fits-all approach to predicting what a patient or family may find to be effective communication. For this reason, this discussion will avoid detailed

discussion of specific communication needs of any particular group, recognizing that no written piece can capture the nuance of specific cultures or the dynamicity of preferences within a particular family. Rather, we will focus on broad themes that illustrate the diversity of preferences across patients from a wide variety of backgrounds, as well as a more general exploration of differing patient and provider preferences surrounding prognostic disclosure. As expectations surrounding difficult communication vary both *between* and *within* cultural groups and families, providers should approach all conversations with curiosity and humility and without preconceived notions of patient preferences.

4.4.1 Patient, Family, and Provider Perceptions Influence Communication

First, it is important to recognize that providers, patients, and families have varied comfort in delivering difficult news, independent of any cultural norms or practices. In a 2015 synthesis of qualitative research surrounding discussing bad news in an oncology practice, Bousquet and colleagues describe both physician-level and patient-level variables that influence the content discussed during a clinical encounter. The authors describe the precarious balance between hope and truth-telling, noting that oncologists may "balance" good news and bad news in an effort to preserve a patient's hope. Furthermore, the authors found that oncologists expressed hesitance to use words like "death," and at times noted that patient emotion, and even their own emotion, influenced the encounter. In addition, the authors noted that there are other systemic factors influencing discussion of difficult news, including time limitations, communication breakdown between different providers, or concerns about not being prepared to deliver difficult news [8].

The tension between hope and truth-telling extends to patients and their preferences, though the impact of prognostic or diagnostic disclosure on the quality of life and patient-reported outcomes is inconsistent. In a recent systematic review, investigators found that the impact of disclosing prognosis to a patient had variable impact on emotional and overall quality of life [9]. Recent data focused on patients with advanced breast cancer demonstrated that though patients initially desired to receive "all information" about their diagnosis, over time they expressed wanting only information deemed "useful;" the authors interpreted this as an effort to preserve hope and meaning in the face of incurable illness, recognizing that patients' preferences shift over time [10]. For these reasons, it is important to approach disclosure of difficult news with a sense of humility and an openness to understanding what a patient or family "wants to know." It is also crucial to remember that a patient may want to know more or less today than they did during previous visits. In some situations, providers may not fully recognize the impact of seemingly "appropriate" disclosures of difficult news on emotional or overall quality of life, highlighting the importance of asking a patient what they wish to discuss prior to information-sharing even if these discussions have happened before.

4.4.2 Impact of Communication Style on Patient and Family Experience

The manner in which difficult news is shared also influences patient and family experience. In one study, cancer patients shown videos of disclosure of a cancer diagnosis using "low" levels of patient-centered communication practices (not identifying emotion, etc.) exhibited increased anxiety and decreased trust in their physician as compared to patients shown a video of an identical diagnostic disclosure, but using "enhanced" patient-centered communication with increased attention to patient emotion [11]. In another study, patients expressed feeling most comfortable when difficult news was delivered in a way that emphasized the patient's preferences, as opposed to focusing primarily on the disease or emotions [12]. In sum—there is not a one-size-fits-all approach, and when in doubt, it is best to check in with a patient about their communication needs.

4.5 Moving Beyond Existing Protocols—Some Actionable Steps

One might find the diversity of patient preferences overwhelming, and for good reason. The data reviewed above underscore how much the content and style of discussing a weighty diagnostic or prognostic "news item" can influence a patient's physical, emotional, and existential well-being. Even patients that are well-known to a clinician may change their preferences surrounding receiving difficult news, further complicating longitudinal discussions of prognosis, values, and goals.

How is a provider to navigate this complex and dynamic area? Here we will suggest several adaptations to the communication maps outlined above, borrowing from different methods and inserting some unique approaches.

Assessing "perception" (SPIKES protocol) [2] *must include not only the patient's perception of the clinical situation, but also the provider's understanding of what the patient wants to know and is ready to hear.*

The above discussion highlights that there is variability in what patients want to know, how they want to receive information, and how they prefer that their families be included in discussions of difficult news. For this reason, it can be useful to ask a patient how they prefer to receive information ("big picture" versus "small details"), who they would like to be present (and who they would like to not be present), and how culture influences communication preferences.

4.5.1 Don't Assume that the Information Shared is "Bad News"

In recognition of the variability of what constitutes "bad" news to a patient, it is important to approach information-sharing with an openness to differing interpretations of the news being shared. Remember that some patients may find news perceived as "bad" by the medical team to be reassuring, or news that is assumed

to be "good" as distressing. A patient's perception can be influenced by their preconceived notions of their disease state, their hopes for the future, and their fears or worries. Our natural desire to give a "warning shot" prior to discussing such news runs the risk of pre-judging the patient's interpretation of the clinical information.

As an alternative, consider prefacing clinical news with a statement such as "I have some information to share with you, and I want to recognize that this may be a lot to take in (or surprising, or unexpected, or confusing, etc.)." In phrasing the "warning shot" in this fashion, the provider identifies the news as impactful, but not necessarily "good" or "bad." This allows the patient to experience the news and their emotions without preconceived framing of their expected reaction. It may also be helpful to ask a patient whether the news was surprising to them, or if they were expecting this information. In this way the patient is able to set the emotional tone for the remainder of the encounter, and provide valuable emotional data to the provider to guide the conversation.

4.5.2 Re-assess, Even if You Know the Patient Well

Particularly over the course of a long-term doctor-patient relationship, there may be multiple opportunities to share medical information, prognosis, treatment options, or other "weighty" pieces of information. It is important to re-assess a patient's communication preferences with each encounter, as well as the communication preferences of the family. In particular, when there is concern that a specific cultural belief may make it difficult for a patient or family member to speak up about their communication preferences, it is crucial for the provider to ask each person present how they would like to participate in communication surrounding new medical information. By setting this as the norm early in a therapeutic relationship, one can potentially empower all family members to fully participate in communication to the extent they feel comfortable.

4.6 Conclusions

In summary, there are multiple methods to disclose difficult or serious medical news. Most of these methods share common themes, including assessing a patient's perception, allowing for and managing emotions, asking permission, adequate preparation, and assessing a patient or family's take-aways from the discussion. However, given the diversity of patient preferences and family dynamics, there is not a one-size-fits-all approach. Above all, it is most important to remember that our definition of "bad news" and a patient or family's definition may not align. Maintaining an openness to being surprised by a patient's reaction, and being willing to ask how a news item "lands" for a patient, are valuable skills that not only maintain patient-centeredness, but also can deepen a therapeutic relationship.

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