

Discussing Prognosis and Shared Decision-Making



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KEYWORDS

- Shared decision-making • Prognostication • Prognostic awareness • Decision aid
- Best case/worst case

KEY POINTS

- Effective conversations in high-stakes situations share similarities with surgical procedures: they are well planned, follow an organized sequence of steps, and use specific tools and techniques to improve outcomes.
- Responding to patient emotion after breaking bad news is an essential requirement before proceeding to discussion of treatment options.
- Shared decision-making is a communication framework that encourages bidirectional sharing of information and promotes relationship-centered care.
- “Best case/worst case” is a decision-making tool that uses scenario planning to paint a picture of life after a particular treatment choice.

INTRODUCTION

In high-stakes surgical situations, decision-making occurs against the backdrop of patients who face life-altering changes in their health. Whether be due to a recurrent cancer, severe trauma, or high-risk acute or chronic surgical illness, patients and their families are in crisis. Confronted with a situation that belies a simple fix, surgeons struggle to balance the hope of improving a problem with the fear of doing harm and prolonging suffering. Nevertheless, surgeons bear the responsibility of guiding patients through high-risk decision-making in these situations that are both medically and emotionally complex.

High-stakes surgical decisions comprise a portion of a bigger conversation, one that usually begins with reviewing a test result or delivering other news that portends

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something serious. The conversations include multiple discrete components: breaking bad news, responding to patients' reactions and emotions, discussing the prognostic implications, reviewing treatment options, eliciting goals and values, making a treatment recommendation, arriving at a decision, and then obtaining informed consent. Surgeons often rely on their training, experience, available standards of care, and evidence-based practice to navigate this tricky terrain with patients. In palliative care training, the investigators learned that it is helpful to organize conversations in distinct phases and apply specific tools to improve communication (Fig. 1). The goal of this article is to review some approaches that surgeons can consider for optimizing communication with patients and families in high-stakes situations.

DISCUSSING SERIOUS NEWS

Many of the difficult conversations surgeons have with patients occur in the context of a piece of data, test result, or "news" that portends a serious, life-altering change. This news may occur in a variety of clinical settings, such as a new cancer diagnosis, surveillance imaging results, a serious traumatic injury, or an acute or progressive chronic surgical problem in a highly comorbid patient. Sometimes, patients are in acute pain and distress. Although the surgeons have become accustomed to these medically and surgically complex problems on a daily basis in surgical practice, this is a pivotal juncture in their patient's life. These discussions require the same care and attention to detail as an operation, with the steps of the conversation planned and thought-out to the fullest extent possible. As with a complex operation, these high-stakes conversations may take unexpected turns that require slight adjustments to specific content or intentional sequencing of each step in the conversation, but the overall structure generally remains the same. Consider the following case:

Mr Johnson is a 70-year-old teacher who presents to the emergency department (ED) with emesis and abdominal pain. He has a history of stage III rectal cancer diagnosed a year ago. He underwent neoadjuvant chemotherapy and radiation, followed by low anterior resection by one of your partners. He has chronic obstructive pulmonary disease, renal insufficiency (baseline Cr 3.5), and rheumatoid arthritis for which he takes daily prednisone. His last surgery was complicated by pneumonia, a 7-day intensive care unit stay, a month in a nursing home, and persistent hypoxemia requiring supplemental oxygen during activity. You are evaluating him in the ED for abdominal pain and emesis. His computed tomographic scan shows a high-grade small bowel obstruction secondary to peritoneal carcinomatosis with evidence of liver metastasis.

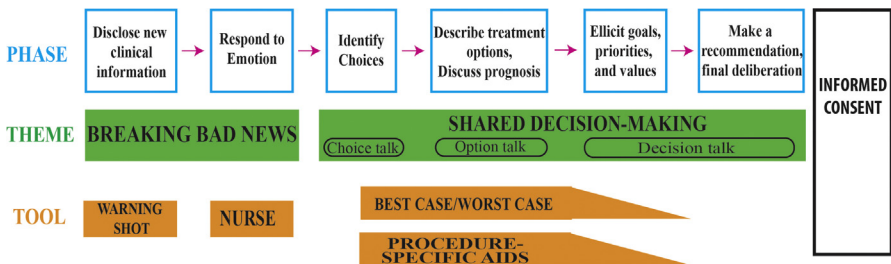


Fig. 1. Organizational guide to breaking bad news, discussing prognosis, and shared decision-making with patients. As conversations progress through phases with distinct themes, specific tools can help surgeons navigate these discussions with patients facing decisions in the context of serious life-limiting illness.

As **Fig. 1** illustrates, surgeons need to cross several hurdles before discussing treatment options and making shared decisions with patients such as Mr Johnson:

- Presenting bad news with a concise “warning shot”
- Responding to the patient’s emotional response while avoiding “cognitive traps.”
- Asking permission and creating space to discuss the implications of the results

Surgeons should expect a strong emotional response when disclosing bad news. This emotion is sometimes disguised as a cognitive question—the cognitive trap—and physicians can easily fall into the trap by responding to the literal question with medical information and ignoring the emotion (as illustrated in **Table 1**). Responding to the emotion, however, is an essential step for the patient in order to process the life-altering medical news and regain the ability to think clearly about medical decisions. Returning to the earlier case, **Table 1** illustrates a surgeon relaying bad news and responding to emotion.

The NURSE mnemonic is an useful tool that categorizes empathic statements that can be used in emotionally fraught conversations (**Table 2**).

Using these phrases and communication tools such as NURSE allows the surgeon and patient to climb down from an emotionally heightened state and return to a place where practical discussion is more feasible. Patients often initiate multiple emotional statements early in these conversations and may require repeated empathic responses before they are prepared to discuss more.¹ Once the emotion has been addressed, it is often helpful to use a question or ask permission to transition across phases of the discussion.

TAB

In this instance, the question “would you like to talk about what that means?” serves as a transition to discussing the significance of a malignant bowel obstruction. This simple question can be quite effective at creating space for a prognostic conversation with patients and may lessen the likelihood of skipping immediately from the discussion of bad news to “next steps.”²

PROGNOSTIC TOOLS AND DISCUSSING PROGNOSIS

With the conversation now headed toward discussing treatment options and possible outcomes, we need to be prepared to discuss prognosis. In these circumstances it is important patients understand that life will not be the same, regardless of the chosen treatment. For our patient with metastatic rectal cancer, it is important to convey that the condition is incurable. This may seem intuitive for the surgeon, but prognostic understanding is not inherently obvious to many patients. Therefore, it is important to withhold assumptions and elaborate on pertinent information when patients have given permission to engage in these discussions. A recent review of patients with colorectal cancers showed that nearly 80% of patients with metastatic disease believed that a cure was likely.³ Prognostic expectations affect patients’ treatment decisions, so it is essential to communicate prognostic information clearly and in a way that has real-life contextual meaning for the patient.

The first step in this process is gathering the appropriate information to frame this part of the discussion. Multiple prognostic tools exist to estimate postoperative outcomes for surgical patients and to estimate mortality risk in various terminal medical illnesses. Most of these prognostic tools are available online. The American College of Surgeons NSQIP risk calculator (<https://riskcalculator.facs.org/RiskCalculator/>) is commonly used and easily accessible for many general surgery procedures. For

Table 1 Surgeon-patient conversation		
Surgeon	Patient	Intent
Mr Johnson, would now be an okay time to discuss the results of your CT scan?	...sure.	Asks permission to discuss results and potential bad news
It's not good news. (pause) The scan shows that your cancer has returned. (pause) It's causing a blockage in the intestines which is why you have pain and nausea. [silence]	What? Are you sure? Dr Jones assured me that I was cancer free. I don't understand. <i>Could you possibly be looking at someone else's CAT scan?</i>	<ul style="list-style-type: none"> Note the concise and measured delivery, done with a thoughtfully measured pace, making sure the patient is ready for the next piece of information. The warning shot "it's not good news" helps organize the patient's thinking for the news, so they do not misinterpret the test results as good or stable news. Leaves silence for expression of emotion Notice the <i>cognitive trap</i> in patient response and watch how the doctor does not directly answer that question but rather interprets it as an expression of shock and responds to that emotion instead.
I can see this is shocking. (pause) I wish I had different news.	I was finally starting to feel better. We were making plans to go visit my kids. [turns to wife, starts to tear up]	<ul style="list-style-type: none"> Avoids cognitive trap (didn't say, "yes, I reviewed the images with the radiologist myself.") Names the emotions seen Notice the surgeon is not immediately transitioning to a treatment plan but leaving space for the patient to process.
You did everything we asked. You did everything right. This isn't fair...	Yeah. It's not. I really wasn't expecting this.	<ul style="list-style-type: none"> The surgeon is continuing to provide space to the patient to process this news by using empathic statements, in this case a praise statement and a statement of understanding.
This is really unfair...	Yeah, it sucks... [silence]... but, what do I do now?	Surgeon is assessing the patient's readiness to move into a treatment discussion.

(continued on next page)

Table 1 (continued)		
Surgeon	Patient	Intent
Well, I mentioned before how the imaging shows that your cancer is back and causing an intestinal blockage... Would you like to talk about what that means?	Yes, I would.	<ul style="list-style-type: none"> Repeats the news; asks <i>permission</i> to move to the next phase of conversation The “what this means?” question is a convention that creates space to discuss meaning of test results, prognosis, and treatment options while giving patients control over the flow of information
Well, it means the cancer has returned. The horrible part about that is it means it is no longer curable. It also means, because of the bowel obstruction, this cancer is now threatening your life. [silence]		

trauma patients, the Injury Severity Score and Geriatric Trauma Outcome Score both model trauma severity and mortality risk. In patients with cancer, validated prognostic nomograms are available through some cancer centers, including Memorial Sloan Kettering and MD Anderson.

When using these tools and risk calculators, it is important to recognize that they provide information in a physician-directed manner.⁴ They speak in the language of percentages and specific complications, which often lack context and meaning if relayed as such to the patient. Cancer survival nomograms in particular are easily misinterpreted by patients.⁵ When relaying prognostic information, it is important to focus on outcomes of relevance to the patient: not just survival, but how their life and daily functions might change in the future. When prognostic information is conveyed in the context of a patient’s quality of life, the discussion of prognosis and treatment options

Table 2 NURSE phrases for responding to emotion		
Skill	Intent	Example
Naming	Acknowledge the emotion that you are noticing	“This must be so devastating to hear”
Understanding	Legitimize the emotion	“Anybody would be devastated to hear this news, it’s so unfair”
Respecting	Praise statements	“You’ve been so brave through all of your cancer treatments”
Supporting	Ally with patient	“This is not what we were hoping for, I will be here with you through this”
Exploring	Seek elaboration	“What are you most afraid of?”

Data from Fischer G, Tulskey J, Arnold R: Communicating a poor prognosis, in Portenoy R, Bruera E (eds): Topics in Palliative Care . New York, NY, Oxford University Press, 2000.

often blend together, which promotes decisions that align with a patient's goals and values.

DISCUSSING TREATMENT OPTIONS: THE LIMITATIONS OF INFORMED CONSENT IN PRACTICE

Providing informed consent is an essential cornerstone of ethical surgical practice, but even when done well the informed consent process is not itself adequate for high-stakes surgical decision-making. Grounded in the ethical principle of patient autonomy,⁶ informed consent focuses on describing the risks, benefits, and alternatives to a particular treatment. In practice, however, obtaining informed consent is unfortunately often relegated to the most junior person on the surgical team to obtain a signature.⁷ Informed consent, when done in this way, often fails to elicit patient goals and preferences, makes no attempt to align treatment options with stated goals, and neglects to offer an informed recommendation. Studies of informed consent for elective and emergency surgery show that patients frequently feel discouraged from asking questions about the proposed treatment options and intimidated by complex forms.⁸ In one study, 22% of patients could not recall which type of physician asked them to sign the informed consent paperwork and 18% reported that they were not given enough time to think about the proposed procedure or the consent form document before they were asked to sign it. Even more disturbing, almost 1 in 4 patients undergoing elective surgery and 2 in 5 patients undergoing emergency surgery agreed that they had no choice but to sign the informed consent document.⁸ Presuming that legal documentation occurs immediately after an appropriate discussion of risks, benefits, and alternatives, these statistics are sobering. Furthermore, when junior level trainees were asked to list the risks, benefits, and alternatives associated with relatively common surgical interventions, as is done in practice, they were only able to answer questions correctly approximately 50% of the time.⁹ When done well by qualified practitioners, informed consent may provide adequate information to patients about a particular treatment option⁶ but it is not designed as a tool to support decision-making.

SHARED DECISION-MAKING

Shared decision-making centers around a physician and patient building a relationship during a deliberative process. In doing so, a patient is supported in expressing values, preferences, and "what matters most" to them, while being provided with the information necessary to make an informed decision. As such, it is neither patient- nor physician-centered, but relationship-centered.¹⁰ The communication framework has been conceptually described by Elwyn as existing in 3 phases:¹¹

Choice talk: Make sure that the patient is aware that there is a choice to be made. Justify that there is a reason this is a *choice*, there is uncertainty about what may happen, and that the right choice may be different for different people.

Option talk: Describe the treatment options and their likely outcomes. Rather than going over a list of potential complications, patients should understand how different options might affect their day-to-day life moving forward.

Decision talk: Elicit patient values and preferences. Discuss these in the context of the treatment options and likely outcomes outlined in (2), providing support in decision-making.

These 3 phases are helpful in arriving at a shared decision that incorporates the surgeon's medical knowledge with the patient's values.

BEST CASE/WORST CASE: A WIDELY APPLICABLE SHARED DECISION-MAKING TOOL

There are several validated tools and guides available to assist with shared decision-making conversations. Some of these tools are generalizable and can be adapted to different situations in which difficult decisions are made. In the authors' experience, one very helpful such tool is "Best Case/Worst Case" (BC/WC). This is a scenario-planning tool based on Elwyn's conceptual model that was designed for "in the moment" decision-making.¹²

An example of the BC/WC, applied to the previous case, is shown in **Fig. 2**. Although this is shown typed here, the authors have found that this scenario planning is best done as a "live" pen and paper diagram completed either just before or while together with the patient. Another example can be found in a training video at <https://www.youtube.com/watch?v=FnS3K44sbu0>.

Information is arranged spatially; each treatment option is first listed side-by-side. For each option, a range of anticipated outcomes is represented by a vertical line with a star at the top (best case) and a box at the bottom (worst case). The length of the line can be adapted to reflect the range of the expected outcome for each option. Finally, circle is drawn along the line to reflect the "most likely" scenario anticipated for each treatment option.

For each treatment option, the surgeon describes and writes down the most important practical outcomes for each scenario. While creating the visual tool with the patient, the surgeon is simultaneously creating a verbal narrative of the outcomes described in the tool. This narrative should be rich in information based on the surgeon's experience but should also emphasize the patient experience of the anticipated outcomes.

The BC/WC tool is effective at promoting the "choice" and "option" phases of Elwyn's model mentioned earlier. After creating the tool and the associated narrative with the patient, the surgeon still needs to elicit the patient's values and provide decision support. This can be done with simple open-ended questions, such as "what do you think about these options?" and "what's most important to you now?" After learning more about the patient's values, hopes, and fears, the surgeon can move on to making a recommendation about how to proceed.

In this case, one can imagine the influence on their recommendation if Mr Johnson were to respond to his BC/WC discussion with "well, after spending a month in the nursing home last time, I just don't think I want to go through that again." In this framework, informed consent is still part of the preoperative conversation, but it occurs only after the part of the conversation in which a decision is reached.

PROCEDURE-SPECIFIC DECISION AIDS

One of the benefits to using BC/WC is that it can be adapted to any patient, regardless of disease process or surgical options. For surgeons who treat a narrower range of conditions, more specific decision aids exist or can be developed to improve communication with patients about particular treatment options. Such aids should guide patients facing a medical decision by making choices explicit, providing easy-to-understand information, and aligning patients' goals and values with their treatment options.

Condition-specific decision aids have shown effectiveness in performing these functions¹³ and they can be adapted in format and setting. Patients with breast cancer confront complex therapeutic decisions as such; this cohort of patients has been studied in the use of surgical decision aids.¹⁴ In a randomized controlled trial, the use of a "Decision Board" by surgeons during clinic visits improved patient knowledge

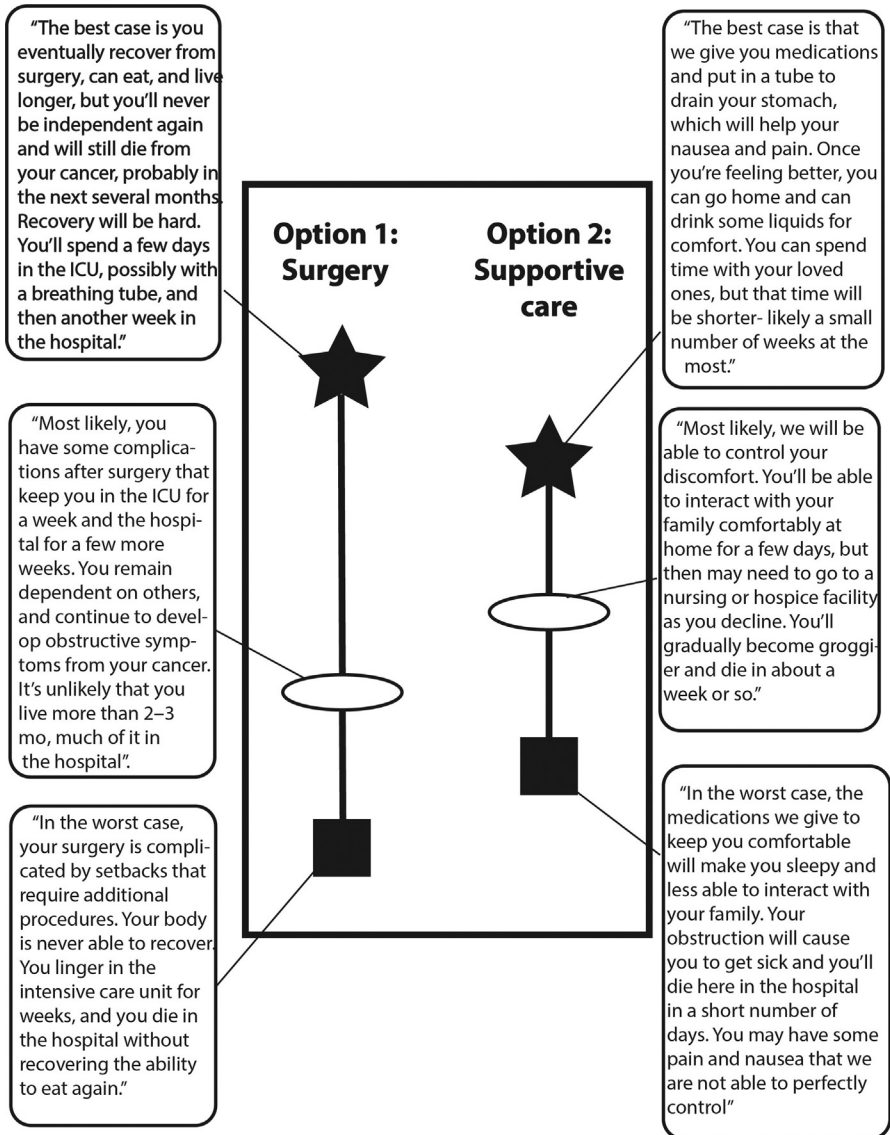


Fig. 2. BC/WC shared decision-making tool. BC/WC visual aid created during discussion with patient. For each treatment option, the star represents the best-case and the square represents the worst-case scenario, with a line connecting the two. A circle is drawn to show the most likely scenario. Notice the line length is longer when the range of anticipated outcomes is wider. In this figure, the texts represent what the surgeon would be saying. In reality, the text on the visual tool would usually be abbreviated bullet points (eg, “Die in hospital”).

and satisfaction with decisions while decreasing decisional conflict.¹⁵ The board consisted of visual and written information comparing mastectomy with breast-conserving multimodal therapy under 4 headings: treatment choice, side effects, results of treatment choice for the breast, and results of treatment choice for survival.

Table 3 Supplementary resources	
Resource	Where to Find
Best Case/Worst Case	https://www.hipxchange.org/BCWC
NURSE Statements	https://www.vitaltalk.org/guides/responding-to-emotion-respecting/
American College of Surgeons NSQIP Risk Calculator	https://riskcalculator.facs.org/RiskCalculator/
Model of Shared Decision-Making	https://jamanetwork.com/journals/jamasurgery/fullarticle/2701816 (see manuscript Figure)

Other aids aim to promote shared decision-making even earlier in the evaluation process. A web-based decision aid given before their first clinic visit effectively improved patient knowledge and decreased the sense of urgency to make a decision.¹⁶

SUMMARY

Surgeons take on a great responsibility when guiding patients through major decisions that affect life-limiting illnesses. Sound decision-making in these scenarios requires patients to understand their prognosis and treatment options and surgeons to understand their patients' values and preferences. Shared decision-making provides a communication model that promotes collaboration around this information. By using conversation tools such as "BC/WC" and other disease-specific decision aids, surgeons can promote more effective relationship-centered decision-making with their patients (**Table 3**).

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