

Serious Illness Conversations: Paving the Road with Metaphors

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ABSTRACT _

Serious illness conversations can influence the direction of care by supporting decision-making compatible with the patient's goals. Effective use of core communication techniques, such as active listening and empathic statements, allows for a deeper understanding of the patients' goals, concerns, communication preferences, and questions. Metaphors can be used to augment

end-of-life care planning. Used inappropriately, metaphors can cause misunderstandings and confusion. Applied skillfully, metaphors can personalize challenging discussions, improving patient comprehension and helping patients and their families to plan ahead. The art of communication is to use the right tool for the right person at the right time. *The Oncologist* 2018;23:730–733

Implications for Practice: Discussions with patients about serious illness concerns are especially challenging for the oncologist. This article provides guidance for preparing for such conversations, including examples of the use of metaphors to personalize and improve communication.

"Metaphors may be as necessary to illness as they are to literature, as comforting to the patient as his own bathrobe and slippers. At the very least, they are a relief from medical terminology. . . . Perhaps only metaphor can express the bafflement, the panic combined with beatitude, of the threatened person."

Anatole Broyard [1]

PATIENT CASE

It is almost 5 o'clock in the afternoon at your medical oncology clinic. Your medical oncology fellow has just seen her very last patient. She comes up to you and says, "Well, this is not going to be easy." She then diligently outlines the patient's history and inquires about strategies to help the patient navigate the complex decisions at the end of life.

You first met this patient 3 months ago, when he was newly diagnosed with metastatic adenocarcinoma of the lung without targetable mutations. After he progressed through first-line carboplatin and pemetrexed, you recommended nivolumab as second-line therapy. Unfortunately, while waiting for this drug to be approved, he developed cauda equine syndrome and became paraplegic and incontinent of urine and stool. He also had severe back pain, fatigue, anorexia-cachexia, and dyspnea. He has just completed a course of palliative radiation to his spine a week prior to this clinic visit and was discharged several days ago.

Today, he presents to your clinic in a stretcher. His wife, the sole caregiver, has moved mountains to arrange transportation

for him to visit your ambulatory clinic. After the waves of bad news in the past month, they are hoping that the oncology team can offer a glimmer of light at the end of the tunnel.

Your oncology fellow initially favored not offering further treatment but is moved by the patient's determination and the wife's persistence. Prior to entering the room, you and your fellow deliberate further on the intricacies of cancer treatment decision-making at the end of life. Given the short life expectancy, poor performance status, and aggressive disease, you both agree that hospice, instead of more cancer treatment, should be recommended.

Cancer treatment decisions at the end of life (i.e., a prognosis of 6 months or less) [2] are intellectually challenging because of the unpredictable future related to life expectancy and treatment benefits and risks and the need to balance many moving targets, such as the patient's wishes, function, and complications and treatment availability. These decisions are also emotionally taxing because of the bond between clinician and the patient, the gravity of the situation, and the daunting task of having to break bad news and discuss death and dying. Now it is time to enter the room to share your recommendations. How do you proceed?

Introduction

Medical oncologists, by the nature of our profession, are faced with challenging decisions and sensitive conversations on a daily basis. Serious illness conversations include discussions on

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a myriad of topics, such as prognosis, goals of care, advance care plans, cancer treatment decisions, and end-of-life care [3].

Longitudinal in nature and punctuated by discrete conversations along the disease trajectory, these discussions can be technically difficult and emotionally draining. As the oncology fellow rightly noted, they can potentially traumatize the patient and family if not conducted properly. At the same time, serious illness conversations can offer patients and their families heightened awareness and insights into the illness, motivate them to actively plan ahead, and empower them to prepare for uncertainty. Indeed, several prospective observational studies have found that serious illness conversations were associated with improved end-of-life care outcomes, such as decreased hospitalization and intensive care unit admissions [4, 5].

During serious illness conversations, some clinicians may choose to use metaphors to help patients to "make the strange familiar" by relating an abstract disease-related topic to one that patients are already familiar with [6]. In a study of audiotaped conversations of 74 oncologists, two thirds of them used metaphors. Importantly, oncologists who used metaphors were perceived by patients to be better communicators [7]. The most common metaphors used by oncologists involve agricultural themes (32%), military (22%), mechanical (19%), and sports (9%). Specifically, metaphors can help patients to better understand the intricacies of illness and facilitate complex decision making. Skillfully applied, metaphors may soften the emotional blow of discussions about death and dying and help patients gain insights into their conditions and foresight into the future [8].

In addition to patients and families, metaphors may help clinicians find more comfort in initiating difficult topics. We previously found that oncologists were much more willing to refer patients to palliative care if the euphemism "supportive care" was used to overcome the stigma [9, 10]. Similarly, clinicians may find it easier to use metaphors to begin end-of-life discussions with some patients. Clinicians who engage in the act of breaking bad news may be perceived by patients to be less compassionate than their counterparts who avoid bad news [11]. Understandably, many clinicians find it challenging to be realistic yet nurture hope while discussing the end of life. They understand that the choice of words during an emotionally charged and intense conversation may make a difference between acceptance and rejection, facilitation and termination, and clarity and confusion.

Metaphors are not always appropriate. Many metaphors in oncology are military in nature (e.g., the "War on Cancer" begun by the National Cancer Act of 1971, "magic bullet," "fighting on," and the cancer treatment "armamentarium") [8]. Families often describe their loved ones as having "lost the battle to cancer" in the obituaries [12]. Some have made the criticisms that military metaphors are authoritarian and adversarial in nature and imply that patients who try harder are more likely to win the battle, whereas those dying from cancer are losers [13–15]. Khullar commented that it is ironic that the "the language of healing remains so interwoven with the language of warfare" [16], and Parikh suggested that "it is time to move beyond the 'war' metaphor to embrace a dual message of surviving and thriving" [17]. Some have called for abandonment of metaphors to minimize ambiguities [18]. Others have argued for a personalized approach with the right metaphors at the right time for the right patient [16, 19, 20], akin to targeted therapy.

Importantly, the primary skills in serious illness conversations involve eliciting patient preferences, beliefs, concerns, and feelings. Metaphors are not meant to replace foundational communication techniques, such as active listening, facilitation (e.g., "ask-tell-ask"), appropriate use of silence, emphatic statements, and checking understanding [21, 22]. For selected patients who require further explanation of abstract concepts, metaphors may be deployed to augment patient understanding. Metaphors may also help some clinicians who sometimes struggle to find the "right" words to initiate discussions on sensitive subject matters related to death and dying. The aim of this article is to illustrate five metaphors that we commonly use in our clinical practice to facilitate serious illness conversations related to cancer treatments, advance care planning, and end-of-life planning. For each example, we provide the clinical context, describe the metaphor, and discuss its potential utility. These metaphors have been used consistently by the authors to facilitate many difficult decisions in both oncology and palliative care settings.

DISCUSSING CANCER TREATMENTS AT THE END OF LIFE: VOYAGE METAPHOR

Patient: "Doctor, I want more treatment, please."

Metaphor: "Every time you get cancer treatment is like going out on a voyage. You hope to have good outcomes, but there is no guarantee. The seas could be rough, and the journey may be hazardous, with unknown danger around the corner. And we want our explorers to be as well informed, nourished, and equipped as possible before they set sail. If they are weak, have difficulty moving around, have lost a lot of weight, and have a lot of pain, they are not only not going to reach their destinations, but very likely get injured during this very stressful trip."

Comment: The goal of this analogy is to help patients understand that if they are not well prepared, it may not make sense to start the voyage (or treatment). By emphasizing harm instead of futility, many patients in our experience can appreciate why no treatment is sometimes the right decision. Although this metaphor may be useful for patients who do not have more treatment options, it may also help patients receiving palliative treatments at any point in the disease trajectory by planting the seed that if they got too weak it may not make sense to embark on another voyage. We also use this metaphor to explain why symptom control is important for patients undergoing treatment and how a supportive or palliative care referral can help them achieving their goal by helping them to be more prepared.

DISCUSSING ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES: INSURANCE METAPHOR

Patient: "What do you mean by advance directives?"

Metaphor: "I talk to all my patients about advance directives because I believe the conversations needed to get ready for these documents are very important to a person's care. By all of us understanding what is important to you and by you and your loved ones having a good understanding of what to expect from your treatment choices, you, your family and your medical team will be better prepared to make whatever medical decisions come down the line. You can then document your wishes

in paperwork called advance directives. This way, if you are ever in the unexpected situation of becoming very sick and not able to communicate your wishes, we have a way of knowing what you want. A medical power of attorney designates someone to be your medical decision maker only if you are not able to tell us your wishes yourself, and a living will describes your wishes. I think about advance directives like I do car insurance. I do not plan on having an accident, but if I do, I will be glad I have car insurance. By having insurance, we have peace of mind driving down the road, and it is a more pleasant ride."

Comment: It is not always easy to ask patients with advanced cancer to imagine the end of life, and it is even harder to explain the abstract concepts behind advance directives. We first normalize this sensitive discussion and emphasize that the documents are for unexpected events. Most patients can grapple with the concepts behind car insurance and understand that just because we do not think that a car accident is going to happen, it does not mean that car insurance is not needed. Although any type of insurance (e.g., property, life) would convey the same message, we use auto insurance because it is the most common. This metaphor may not work as well for patients who drive without insurance (which they rarely admit) or do not own a car. In these cases, health insurance may also work. In our experience, after the car insurance discussion, many patients are willing to take a look at these documents, and some will even take immediate steps to complete them.

REFERRAL TO PALLIATIVE CARE: TAKING A ROAD TRIP

Patient: "I don't understand why you want me to see supportive/palliative care."

Metaphor: "The cancer journey is like taking a road trip, and the goal is to get to the destination, which is to treat the cancer effectively. Some drivers just want to get to their destination and don't pay enough attention to comfort and safety features, such as the seat belt, spare tire, and seat cushion. Others take advantage of these additional features so they can get to their destination safely and more comfortably. Because these drivers are more prepared, they may be more likely to achieve their goals. By the same token, the supportive care doctors can help you with your symptom control along the cancer journey, so they can be the cushion helping you to tolerate cancer treatments better. They can also offer roadside assistance so you feel safer along the road trip."

Comment: This metaphor is used to help patients understand why it is important to address supportive care issues concurrently with active cancer treatments [23]. It emphasizes the comfort features (e.g., symptom control) and safety features (e.g., care planning). Furthermore, it offers some realistic (or achievable) hopes to complement other care goals.

EARLY REFERRAL TO HOSPICE: CATCHING A PLANE

Patient: "I don't want to think about hospice yet."

Metaphor: "Tell me more... Well, this is a difficult topic and I can see why many patients do not want to think about it. At the same time, it is important to be prepared for what may lie ahead. It is like you are going to catch a plane. If you decide to start packing 2 hours before the plane takes off, you are more likely to forget your passport or other important items.

Furthermore, it is more stressful, and you may even miss the flight. If, on the other hand, you have packed a few days ahead of your travels, you are likely to be more relaxed and better equipped. Thus, although you may not need hospice at this time, I would encourage you and your family to start to learn more about hospice. You could perhaps interview some hospices to see what they offer, so you can be well informed if and when you need it. Let me know when you are ready."

Comment: Hospice referral is often delayed. This metaphor communicates the need for patients and caregivers to think ahead and to be prepared. It normalizes the stigma around hospice decision making by comparing it to an upcoming trip. This metaphor subtly implies that there is likely a looming deadline to make decisions about hospice care, acknowledges that this decision is stressful by nature, and provides two key reasons why patients may not want to procrastinate (i.e., to be more prepared and less stressed). Of course, it is ultimately up to patients to decide if they are ready to be referred or not.

INVOLVING FAMILY IN CARE PLANNING: TEAMWORK METAPHOR

Patient: "No, I have not been talking much about this with my family."

Metaphor: "The time ahead is likely going to be challenging, and this is a time when you will need teamwork more than ever. You are the captain, and you will need to decide who should be on your team, share with them your vision, and clarify each of their roles so they can be most helpful to you and you to one another.

"Based on how you have been doing so far, you are likely to get weaker and will need more help. Have you thought about who will help you with your daily activities if this happens? As a team, it is also important to look out for each other and to make sure your key caregivers don't burn out. If you haven't already done so, it may be a good idea to start asking people close to you, such as family members or friends, who can help out sometimes. Many people want to help, and you need to tell them how. By taking the lead, you can also find out how you can better support your team members (your family). We are also on your team and will help you with as much as we can from the medical standpoint. If you agree, I would like to recommend some home care services for you."

Comment: This simple metaphor highlights many aspects of end-of-life care planning, including the leadership role of the patient, the need to communicate closely among families, the importance of setting goals of care, the coordination of different team members, and the involvement of medical as well as personal support. In our practice, it is often discussed in conjunction with hospice care.

CONCLUSION

Serious illness conversations are serious discussions and can modulate the direction of care by supporting decision making compatible with the patient's goals. Serious illness conversations require careful preparation, experienced clinicians to facilitate a dialogue, and a cohesive team who can provide further support and follow-up. Effective use of core communication



techniques such as active listening and empathic statements allow the clinicians to gain a deeper understanding of the patients' goals, concerns, communication preferences, and questions. Based on the clinicians' assessment of the patient's intellectual comprehension and emotional readiness, metaphors may be deployed sensibly to augment end-of-life care planning. Used inappropriately, metaphors run the risk of misrepresentation, confusion, and overinterpretation. Applied skillfully, metaphors may augment clinicians' ability to personalize many challenging discussions and help patients and families actively plan ahead. The art of communication is to deploy the right tool for the right person at the right time. More research is needed to examine how metaphors can be optimally deployed and their impact on patient outcomes.

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DISCLOSURES

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