

## When Open-Ended Questions Don't Work: The Role of Palliative Paternalism in Difficult Medical Decisions

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### Abstract

The balance between patient autonomy and medical paternalism must be reexamined. The tension between autonomy and paternalism is both an ethical and practical issue. Autonomy is the current gold standard approach to patient communication and has grown to the point that patient preference dictates care, even when their choices are not possible or are medically nonbeneficial. Furthermore, we have observed a trend among physicians to avoid making difficult medical decisions by hiding behind a shield of patient autonomy. Paternalism, characterized as the antithesis of autonomy, is widely dismissed as having any role in medicine. We disagree and believe that paternalism still has an important role in medical decision making.

### Mrs. A

MRS. A IS A 53-YEAR-OLD WOMAN with end-stage liver disease secondary to primary biliary cirrhosis who came to the United States to be evaluated for possible liver transplant. Eight months ago she was placed on the transplant list and she and her husband rented an apartment to stay near the hospital. They have four children back home in Saudi Arabia.

Over the last several months she has had eight admissions to the hospital for various reasons. She was again admitted two weeks ago for altered mental status. During her hospitalization her health deteriorated and she was transferred to the intensive care unit with septic shock requiring two vasopressors to maintain adequate blood pressure and mechanical ventilation for respiratory failure. She also had acute renal failure, acidemia, ileus, and severe malnutrition. To clarify goals of care, the hepatology attending used an Arabic telephone interpreter to communicate with the patient's husband. The hepatologist finished the conversation and reported to the critical care team, "The husband does not want to give up. He wants us to do *everything*." Despite several days of maximal critical care, she continued to deteriorate. The medical professionals involved in her care felt that she would not survive the hospitalization.

The critical care and palliative care teams met with her husband and asked what he understood about her condition. The husband responded, "Only God knows at this time. We must put our faith in God, but I don't want her to

suffer." The critical care attending attempted to educate the husband regarding her multiple medical issues, but the husband continued to repeat, "Only God knows." The critical care attending inquired about the continued use of vasopressors and mechanical ventilation. The husband said he could not make that decision because he felt as if he was killing her and could not live with the burden of this decision. The critical care team accepted the husband's desire to continue maximal, life-prolonging therapy and the patient died after several rounds of cardiopulmonary resuscitation.

### Introduction

Historically, medical decision making has been rooted in paternalism, with the physician cast as the wise healer and the patient as the passive recipient of care. The 1847 Code of Medical Ethics of the American Medical Association called for the prompt and implicit "obedience of a patient to the prescriptions of his physician" and forbade consideration of the patient's "own crude opinions."<sup>1</sup> Although the paternalistic approach intended to act in the best interest of the patient, it fell short because this approach did not account for the patient's views in the decision process.

The shift from paternalism to autonomy in the United States began in the 1950s with the revelations of patient experimentation from the Nuremberg trials, out of which came the concept of informed consent.<sup>2</sup> The combination of informed consent and the increasing availability to the general

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public of medical literature fueled the patient's participation in medical decision making. Since this shift away from paternalism toward autonomy, there has been a generally negative perception of the role of paternalism in medicine. In fact, paternalism is considered the outdated antithesis of autonomy.

The pendulum has swung from a "doctor knows best" philosophy to an era of "patient knows best," with patients dictating an increasing portion of their care (Fig. 1). Today, some may argue the pendulum has swung to an autonomy extreme described as a "tyrannous" predominance of patient autonomy resulting in costly, ineffective, and even harmful medical care.<sup>3-5</sup>

Informed consent and the growing role of autonomy in medical decision making led to unintended consequences. Physicians began to abdicate their medical expertise to make complex medical decisions and deferred to their nonexpert patients and surrogates.

Consequently, a more balanced approach to clinician-patient communication and medical decision making evolved called *shared decision making*, which Kon later described as the "shared decision making continuum."<sup>6</sup> Kon's model attempted to navigate the tension between paternalism and autonomy in medical decision making and described "patient- or agent-driven care" on one end of a continuum and "physician-driven care" on the other end.<sup>6</sup> The introduction of this continuum described the clinician's role in determining the appropriate level of patient autonomy when addressing treatment decisions. Kon highlighted that "the types of decisions that call for different approaches cannot be categorized because each patient is different and it is the patient, not the decision under consideration, that guides the process."<sup>6</sup> As a result, the clinician's assessment of the patient became essential in determining the appropriate level of autonomy within the context of shared decision making. Specifically, clinicians must take into account certain factors when approaching communication surrounding medical decisions, such as patient values, culture, personality, psychosocial history, coping style, the limitations of medical science, and, of course, the disease.

*Palliative paternalism* is an approach to communication with limited open-ended questions that utilizes well-informed, discrete, concrete options during medical discussions, in order to reduce confusion and suffering by avoiding nonbeneficial care. Palliative paternalism provides a communication approach that determines the appropriate level of patient autonomy. We believe that open-ended questions and unlimited care options may cause more harm or suffering in some patients and/or surrogates.

Most importantly, palliative paternalism must always be grounded in compassion for patients, as well humility, recognizing the limitations to understanding many aspects of each individual's illness experience.

## Scope of the Problem

### *Medical experts deferring to nonexperts*

Clinicians undergo many years of training in numerous settings, building a unique skill set that enables them to provide an expert opinion and make complex medical decisions. Much like a skilled mechanic does not expect the customer to decide how to fix a car, the expert clinician

should not expect patients to make complex medical decisions without expert guidance and support.

### *Medical decisions during learned helplessness*

Patients and surrogates often must make critical medical decisions at times of incredible stress—a time when they are least able to fully engage cognitively in the medical decision process. Sullivan and colleagues describe a phenomenon of learned helplessness, the consequence of experiencing uncontrollable events among surrogates in the ICU.<sup>7</sup> Learned helplessness may result in disengagement from the decision making process and may lead to defensive behavior such as avoidance and withdrawal. Continuing to push for a decision in this situation may lead to more defensive behavior and reluctance to make decisions.

### *The burden of decision making*

Expecting patients or family members to make life or death decisions is a tremendous weight. Yet, it has been our observation that as patients approach death, medical providers frequently defer these decisions to patients and/or loved ones. Medical providers frequently begin these conversations with, "Do you want...?" This implies there is a decision to be made. Medical providers ask this hoping the patient and/or family will say, "No more." However, this unintentionally causes the patient and/or loved ones to feel as if they are "pulling the plug," shifting the conversation from a rational to an emotional one. On the other hand, patients and/or loved ones want the medical providers to make the decision so they are not responsible for "killing" themselves or a loved one. No one wants to be responsible for "killing" someone. It is an awkward dance where neither wants to take the lead. Often the truth is that there is no decision to be made and there is no burden to bear. The conversation needs to be reframed to clarify that the patient's disease has already made the decision and is the cause of death.

### *Clinician fear and defensive medicine*

At times clinicians worried about litigation will offer exhaustive lists of medical options to patients and then defer the decision to the patient rather than provide medically appropriate focused guidance. This promotes a false sense of control for patients in the acute care setting. We have heard the term *defensive medicine* used by clinicians to justify deferring medical decisions to the patient in complex and high-risk medical situations. However, there is no evidence that limiting medical options leads to litigation. In fact, the opposite is true. Clinicians are more likely to be sued if they pursue aggressive treatment against patients' explicit wishes to the contrary.<sup>8,9</sup>

### *Patients are more than the sum of their parts*

Given the growing number of available treatments, medicine has become very specialized and compartmentalized. Medical specialists focus on specific organs, not the entire patient. Patients may have multiple specialists involved in their care, each with a unique and narrow focus. The patient is likely to be seen as a sum of parts rather than a whole person. For example, the hepatologists may tell the patient that the liver's synthetic function is adequate, implying all is well;

meanwhile, the patient's renal function is failing. The number of specialists involved and the hurried pace within the hospital create many obstacles to effective communication. Consequently, specialists use patients as communication conduits with other specialists, asking patients what other specialist services have told them. Without the ability to synthesize this fractured, organ-specific, and often conflicting information, patients become frustrated and confused. As a result, patients and families may cling to fragmented messages that emphasize improvements while rejecting contrary information describing any decline.

### **Lapses in truth telling**

Truth telling occurs between medical colleagues and not between the clinician and the patient. It is common for clinicians to honestly discuss the patient's overall state and prognosis outside the patient's room, while presenting a glossed version to patients. The lack of truth telling with the patient may lead to requests for nonbeneficial interventions that would not otherwise occur if the patient had a clearer understanding of the disease and prognosis.

### **Approach**

Presenting medical treatment options that are unavailable or unlikely to benefit the patient increases patient suffering. This can be avoided if clinicians provide clear, medically appropriate direction.

### **The illness communication continuum**

The illness communication continuum (Fig. 2), a spectrum with absolute patient/surrogate-directed communication at one extreme and clinician-directed communication at the other, describes communication in the medical setting. Where a given conversation might fall along this continuum is dictated by two factors: disease trajectory (prognosis) and/or the patient's or surrogate's capacity to cope.

As disease advances and prognosis worsens, the patient loses autonomy and viable treatment options become fewer. This occurs as a natural result of physiological changes in the disease process. As the patient approaches death, the clinician plays a larger role in decision making, not by taking control, but rather by identifying viable medical options.

### **Coping and the illness communication continuum**

Coping is the ability to respond to stress, or the "capacity for resilience and personal growth in the face of challenge."<sup>10</sup> A patient's coping dictates where along the illness communication continuum a clinician should engage a patient in difficult medical discussions. When a patient is noted to be coping ineffectively, regardless of their prognosis, we advocate a shift to a more clinician-directed approach.

The construct of coping is very fluid. Applying labels of "good" or "bad" or "poor" when describing another's coping may seem judgmental or pejorative. We suggest that evaluating a patient's coping is an assessment, not a judgment. We all regress (return to an immature way of coping) when under stress. For example, a mature five-year-old may begin to wet the bed when a new sibling is born. That child needs some time to regain their emotional equilibrium, while

being supported in a loving, predictable environment with consistent and compassionate direction. All people need time, support, and consistent direction to regain emotional balance and move on when facing very threatening circumstances. Sometimes regaining that balance requires a significant amount of time and in other circumstances, just a few minutes. The best predictor of current or future coping is past coping. Some of us take a breath and move on, while others of us may require hours, days, weeks, or even months. Patients whose coping recovery is more protracted will benefit from a more clinician-directed conversation.

For the purposes of simplifying a fluid concept, we have artificially polarized and simplified quick emotional recovery as adaptive coping and protracted emotional recovery as maladaptive coping (see Table 1). *Adaptive coping* is characterized by seeking social support for emotional reasons, positive reinterpretation, acceptance, faith, and humor, to name a few. *Maladaptive coping* is impulsive and driven by emotion, not reason, and includes denial, mental disengagement, behavioral detachment, focus on and venting of emotions, and the use of alcohol and drugs, among others.<sup>10</sup>

Clinicians will successfully communicate with patients using open-ended questions if they are capable of adaptive coping. Clinician-directed communication should be avoided in patients with adaptive coping, as a direct approach with limited options may be interpreted as condescending or patronizing and usurp trust and communication.

Patient-directed communication in patients with maladaptive coping should be avoided as it can lead to increased patient suffering, poor medical care, and set the stage for complicated bereavement for loved ones.

### **Palliative paternalism: An approach to advanced disease and maladaptive coping**

Prior to meeting with the patient regarding an important medical decision, take note of any potential risk factors for maladaptive coping (see Table 1). Characteristics of those patients at risk for increased suffering in the setting of unlimited care options include patients who are medically

#### **Case example: "Everything done"**

Ms. G was diagnosed at age 30 with a stage II colon cancer, which was resected and treated with chemotherapy. She relapsed one year later and elected to receive multiple additional standard treatments as well as many alternative treatments, such as squid ink enemas. She and her family expressed immense gratitude toward her medical oncologist for "allowing" these nontraditional therapies. She frequently reiterated her desire to "do everything" she could to stay alive, but clarified if she were to die that she preferred to die at home. As her disease progressed and she continued to physically decline, her doctor limited potentially harmful treatment options and made clear recommendations for medically appropriate interventions at the end of life. Her doctor gave her a clear recommendation against cardiopulmonary resuscitation. Her physician ultimately helped her receive in-home hospice care in order to honor her choice to be at home in her last days. She died a week after returning home.

TABLE 1. RISK FACTORS FOR PROTRACTED EMOTIONAL RECOVERY OR MALADAPTIVE COPING

**Cognitive**

- Cognitively delayed—inability to consider two opposing options at the same time or unable to conceptualize possible outcomes
- Medically naïve—may view the human body similar to a car; discrete parts that work together but have no real interaction
- Extremes of age—young or old (dementia)

**Emotional/psychological**

- Emotionally arrested
- Shame is a prominent emotion; patient may inaccurately believe it is his or her fault he or she is sick
- Posttraumatic stress disorder
- Emotionally reactive
- Serious mental illness
- Magical thinking
- Need to assert own authority in spite of possible harm to self
- Substance abuse

**Social/cultural**

- Cultures that are traditionally mistrustful of the medical community
- Cultures that focus on the collective rather than the individual
- Cultures that value deference to authority
- Individuals who believe only option is a miracle

naive/illiterate; patients with rigid or limited coping skills; patients who belong to cultural groups mistrustful of the medical community based on historical events; and patients with a history of substance abuse, serious mental illness, or a personality disorder.

When using patient-directed communication, begin with the standard open-ended questions such as, “What have the doctors told you about what is going on?” (see Fig. 3) The open-ended question is always the default initial approach when communicating with patients for the first time.

When an open-ended question is met with a protracted emotional response, this may be due to maladaptive coping. Examples of a strong emotional reaction include such state-

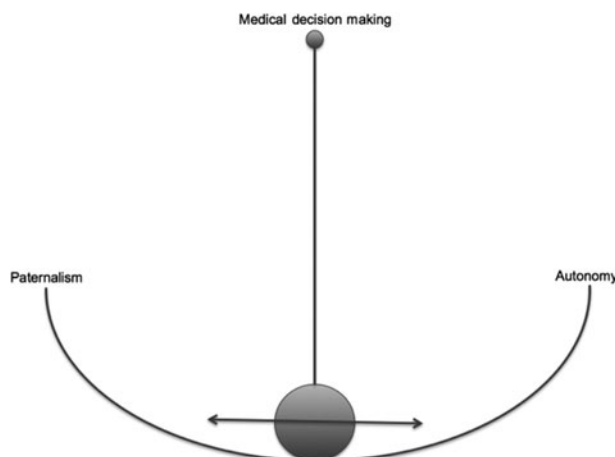


FIG. 1. The medical decision making pendulum.

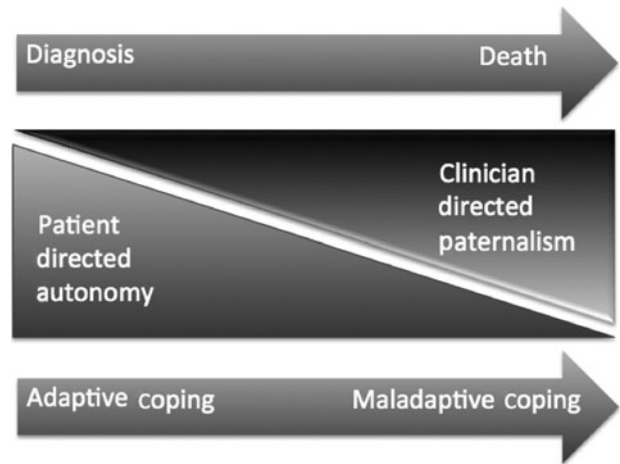


FIG. 2. The illness communication continuum.

ments as, “You should know what’s going on, you’re the doctor!” or “I don’t know, they don’t tell me anything.” Other indicators may include fixation on a specific point, or repeating statements and questions. For example, “I don’t understand why you can’t just operate to take out the cancer!” or “But the doctor said the labs were improving.” In this situation, rather than repeat another open-ended question, make a clear declarative statement about the medical situation:

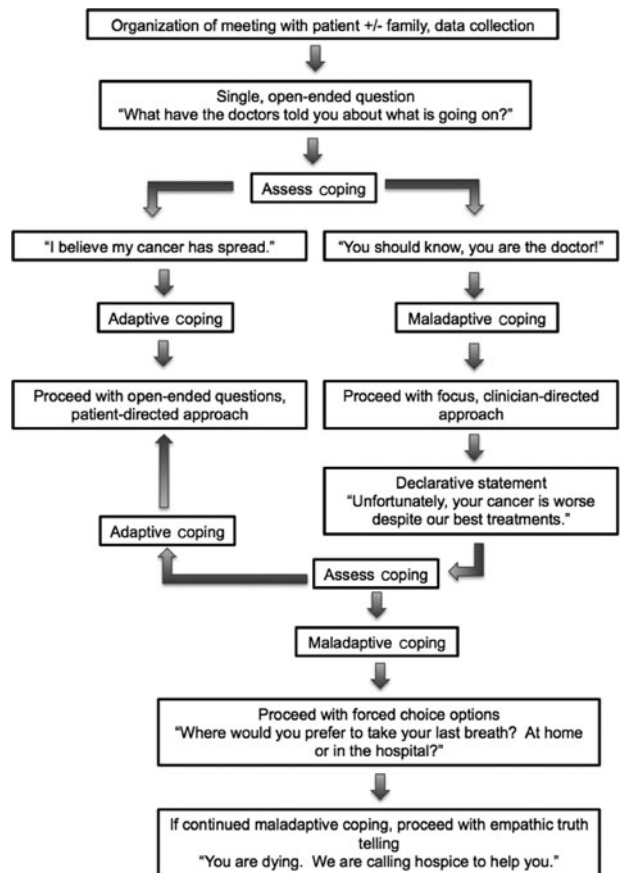


FIG. 3. Approach to medical discussions based on assessment of patient coping.

- “We are at the end of what medical science can offer to cure or slow the disease.”
- “Unfortunately your life is going to be shorter than you hoped.”
- “The disease is progressing despite the very best treatment.”

Following this declarative statement, pause and observe the reaction, responding with empathy and validation as appropriate. If the response is met with adaptive coping, the clinician might try another open-ended question. If the response continues to demonstrate maladaptive coping, further directive statements should be used:

- “We will do all we can to make sure you are comfortable.”
- “Unfortunately, we cannot correct this with a surgery.”
- “We will not perform CPR or start a ventilator because it would not help in any meaningful way.”

Again, these conversations must be accompanied by compassion and humility or they will be interpreted as coercive and cruel. To those unaccustomed to direct communication about such difficult topics, these statements may seem blunt or even harmful. However, circumventing the truth because it is uncomfortable is unprofessional and may increase patient suffering. Clinicians should not avoid difficult conversations to protect themselves. Conversely, if these

#### *Maladaptive coping example: Emotional reaction*

Mr. B, a single, Caucasian, 40-year-old male with an extensive history of heroin abuse, was admitted to the hospital with fever, cough, and severe pain due to widely metastatic lung cancer. The palliative care service was consulted for symptom management to discuss goals of care. Despite recent chemotherapy, his disease has progressed rapidly. Given his poor functional status and refractory disease he has a prognosis of hours to days.

MD: “So I think it’s time, Mr. B, to seriously consider hospice. What do you think?”

Patient: “I don’t know, doc. I get such good care here; I’m afraid my pain won’t be controlled.”

MD: “Well, hospice specializes in pain control. What do you think?”

Patient: “I just don’t want to die, doc. I need to wait until my mom gets here.”

MD: “I know you don’t want to die and we don’t want you to either. I wish things were different.”

Patient: “I want to be strong, but don’t know how much more pain I can take. I don’t want to die.”

Palliative care clinician: “Mr. B, I’m going to have someone from hospice come talk to you. It would be best for you to go to the inpatient hospice unit where they can control your pain. Would you like me to let your mother know this, or should you let her know?” (palliative paternalism)

Patient: “Okay....Will you help me tell her?”

techniques are used appropriately, they can provide immense relief by providing clear direction and support in the most difficult moments.

#### **Mrs. A Revisited**

Mrs. A is the 53-year-old woman with end-stage cirrhosis and sepsis described at the beginning of this article. The palliative care nurse practitioner asked the patient’s husband what he knows about his wife’s medical condition. The husband responded, “Only God knows at this time. We must put our faith in God but I don’t want her to suffer.” The critical care physician attempted to educate the husband regarding her multiple medical issues, but the husband continued to repeat, “Only God knows.” In response, the critical care attending quickly began to offer the continued use of vasopressors to keep her alive. Recognizing maladaptive coping, the palliative care nurse practitioner, wanting to use palliative paternalism, gently interrupted the conversation and asked, “Do you think your wife is suffering now?” The husband responded by saying, “Yes, but I am not sure. Only God knows.” In response, the nurse practitioner voiced to the husband, “Unfortunately, despite maximum medical interventions, your wife is dying. There are no decisions to be made because her body and disease have already made the decision. At this time we will ensure she has a peaceful, comfortable death.”

The patient’s husband was very saddened, but voiced his understanding and was grateful for the compassionate care she had received in the hospital. Shortly after the meeting the vasopressors were stopped and the patient was given intravenous opioid boluses for pain and shortness of breath. A Muslim critical care nurse spent the patient’s final hours with the husband and was able to pray with him. The patient died about one hour later with her husband and the interpreter at her bedside.

#### **Author Disclosure Statement**

Dr. Roeland reports serving on the data safety and monitoring board of Cellceutix and the external advisory board for Lilly USA. All other authors have no disclosures to report.

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