Adaptive Leadership: A Novel Approach for Family Decision Making

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Abstract

Family members of intensive care unit (ICU) patients want to be involved in decision making, but they may not be best served by being placed in the position of having to solve problems for which they lack knowledge and skills. This case report presents an exemplar family meeting in the ICU led by a palliative care specialist, with discussion about the strategies used to improve the capacity of the family to make a decision consistent with the patient's goals. These strategies are presented through the lens of Adaptive Leadership.

Introduction

FAMILY MEETINGS are a routine way to provide information and support to family members facing end-of-life (EOL) decisions in the intensive care unit (ICU). Researchers and medical educators have recommended guidelines for conducting ICU family meetings using a model of shared decision making and a communication framework, which includes: setting the stage, giving clear information, responding empathically, avoiding too much technical detail, and making recommendations about treatment.¹⁻³ Despite these guidelines, providers often approach EOL decisions only as technical challenges, using authoritative expertise while ignoring the adaptive work that families must do⁴ as they accept a radical change from one of hope that the patient will survive to acceptance that the patient is dying.

Adaptive Leadership is an organizational management principle⁴ that describes individuals and organizations as complex adaptive systems that adjust to changing internal and external environments through a self-organizing process.⁵ By emphasizing the need to address the challenges people face when adapting to change or loss,⁶ the Adaptive Leadership principle provides a useful framework for facilitating family member decision making in the ICU, where decisions are often complex and involve uncertainty. A mistake often made in organizations, as well as in medicine, is to address change as purely technical through the use of authoritative expertise while ignoring the adaptive work that the stakeholders must do for themselves.^{4,6}

The framework of Adaptive Leadership proposes two types of challenges, technical and adaptive, each resolved in different ways.⁴ Technical challenges have a clear problem

with a technical solution,^{4,6} such as placing a chest tube for a pneumothorax. The clinician does the work by using his/her expertise to determine the diagnosis and treatment with little involvement of the patient or family. Adaptive challenges involve complex problems that cannot be solved with a technical intervention and cannot be solved by expertise alone.^{4,6} For adaptive challenges, the stakeholder (the patient and/or family) must do the work of recognizing the problem and figuring out a solution.⁴ The clinician supports the stakeholders as they let go of old beliefs and strategies that may be comfortable but no longer effective and as they accept new understandings, beliefs, and behaviors.^{4,6} Thus the clinician's role is to provide Adaptive Leadership. Table 1 summarizes differences between technical and adaptive challenges and work.⁴

In a patient with co-morbid chronic illnesses and uncertain prognosis, who may be facing EOL, the challenge of a pneumothorax is no longer just a technical challenge with a technical solution. The decisions for such a patient are complex and present challenges that necessitate the use of adaptive as well as technical solutions. Technical challenges, such as whether and how to use life-supportive technologies and manage pain and symptoms, are accompanied by adaptive challenges that may require family members to recognize that the patient is dying, reevaluate what they are hoping for, and cope with the impending loss.

As family members realize that technical solutions are not going to preserve the life and well-being of their loved one, they are faced with trade-offs, including balancing quality of life with preserving life at all costs. They may struggle with decisions such as whether to lighten sedation so that they can interact with the patient, knowing that if the patient is awake,

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TABLE 1. TECHNICAL VERSUS ADAPTIVE CHALLENGES AND WORK

<i>Technical challenges</i>	<i>Adaptive challenges</i>
<ul style="list-style-type: none"> • Problem: Simple or complicated • Solution: Clearly defined technical intervention based on evidence or expertise • Work: Expert identifies and implements the appropriate solution. 	<ul style="list-style-type: none"> • Problem: Complex with multiple interrelated elements • Solution: Ill-defined, uncertain • Work: The work is done by the stakeholder (the patient and/or family) not by the experts (clinicians). <ul style="list-style-type: none"> ◦ Recognize and solve the problem. ◦ Change attitudes and beliefs. ◦ Involves loss and trade-offs ◦ Technical solutions alone do not solve the problem.

Source: Thygeson et al., 2010.

he/she may suffer. Using the framework of Adaptive Leadership in the ICU family meeting, the role of the clinician is to first recognize that the family must do the adaptive work of letting go of beliefs and hopes for cure and adopting new beliefs and hopes for palliation and peaceful death.^{4,6} The clinician following this principle interacts with the family by providing information and guidance to support the family in making decisions consistent with the patient's goals.^{4,6}

The purpose of this case report is to present an exemplar family meeting in the ICU led by a palliative care specialist, to discuss his reflections about the strategies he used to improve the capacity of the family to make a decision consistent with the patient's goals, and to present these strategies through the lens of Adaptive Leadership.

Methods

The data for this case report were gathered in a pilot study of family decision making in the ICU. With Institutional Review Board (IRB) approval and consent from participants, we audio-recorded a family meeting in a tertiary teaching hospital in the southeast United States, led by a palliative care physician. After he reviewed the meeting transcript, this physician agreed to be interviewed to explain his techniques for building the family's capacity to make decisions consistent with the patient's goals. The data used in this manuscript consist of the transcript of the family meeting as well as the transcript from the interview with the palliative care physician.

Case Description

The patient was a 68-year-old male with sepsis and acute respiratory distress syndrome (ARDS). Despite the presence of a "Declaration of a Desire for a Natural Death," the patient was on a ventilator, vasopressors, and did not have a do not resuscitate (DNR) order. The family meeting included his wife of 40 years, two adult sons, a daughter-in-law, two nurses, the palliative care physician (Dr. PallCare), a pulmonary Fellow (Dr. Fellow1), and three resident physicians. Halfway through the meeting, a second Fellow (Dr. Fellow2), with whom the family had a good rapport, joined the meeting. Pseudonyms are used.

Introductions

Dr. PallCare began by introducing everyone and setting the tone, saying, "When you're in a tough situation like Mr. B, we should be in close touch and talking." He asked the family what they understood about Mr. B's condition and then re-

viewed his condition, focusing on the poor prognosis and the big picture. He demonstrated compassion, gave foreshadowing of bad news to come, and verified that the prognosis was poor, saying, "I wish I had better news." Reflecting on his opening remarks, Dr. PallCare explained his purpose as "allowing them to come to the same conclusion that I had after looking at everything, which was that the prognosis was bad." This set the stage for the adaptive work that the family needed to do.

Giving the family information

Dr. PallCare asked the family what the patient would prefer under these circumstances if he were able to tell them. The wife remembered that in a past health event he wanted "everything done." Son2 recalled Mr. B expressing that "artificially supported life is not really life." Dr. PallCare explained that ARDS was fatal, emphasizing "we don't want him to suffer...I want to make sure we are doing things for him [instead of] to him." On reflection he stated, "It's important to let the family know when someone is dying." In the language of Adaptive Leadership, Dr. PallCare assisted the family to see the potential for loss and begin to adapt to a new reality.

Dr. Fellow1 answered questions about ARDS by giving a long explanation of the pathophysiology. On reflection, Dr. PallCare commented on this technique:

Reading the transcript, I can tell he is not experienced with this, and he is going down the wrong path and counter to what I was doing, which is "find out what they know, correct any misinterpretations, and ask them what the patient would want." The Fellow is talking way too much, using jargon, and becoming an "explainaholic," which never helps a family.

Although Dr. Fellow1 was trying to help the family transition, his tactic is an example of using a technical approach to an adaptive problem.

Framing the issues

Son2 asked if the patient could hear them and if they could remove the endotracheal tube and lighten the sedation enough to have a conversation with him before he died. Thus he faced another adaptive challenge, the trade-off between maintaining the comfort of the patient and losing the chance to communicate last words. The daughter-in-law voiced an understanding of this trade-off: "I don't think there is anything left that any of us needs to say if it's going to cause him pain."

At this point, Dr. Fellow2, with whom the family had developed a close relationship, entered the room and after a technical explanation of ARDS said, "But we're happy to decrease the sedation, and if he starts looking uncomfortable [we can increase] it very quickly." Whereas Dr. PallCare's response was to focus on what the patient would want, Dr. Fellow2 offered a technical solution to an adaptive challenge.

Son1 asked about the lab values, to which Dr. Fellow2 responded by giving a long explanation. Dr. PallCare then refocused the conversation back to the big picture saying: "My dad died in ICU here, and what I would tell you is, the numbers are kind of important but also irrelevant; we need to help you focus on the big picture."

Son2 replied, "So, it sounds like [begins to cry]...there's no way he's ever going to get out of [the] ICU," to which Dr. Fellow2 responded:

The truth is, no. I wish that I could come here with an encouraging nod or say, he's going to get better, but we went through everything this morning, and when I looked at that chest x-ray, unfortunately, there was nothing encouraging there.

Son2 responded with some humor, "He owes me 20 dollars. I gotta get that from him." Dr. PallCare replied, "He'll remember that. The last thing my dad said to me was, 'Who's gonna get this bill?' So, dads are like that."

Reflecting on this exchange, Dr. PallCare said, "Dr. Fellow2's response was a great wish statement. Dr. PallCare described an Adaptive Leadership perspective when he reflected that:

Our subspecialists have been taught that if you give family enough information, they will make the same decision that you will. Data are important, but it's not what matters most to the family. They want to know, "Is he suffering, can I talk to him, if we did this would he be able to chat with us, but would he suffer from it?" So we are very information oriented, and they are very "How's he doing?" oriented. What I do is try to connect with them on a family level. I ask myself, "If I'm in this family, what is it I hope someone tells me so that I can make good decisions?"

Dr. PallCare described a clear example of the difference between technical and adaptive approaches. This family needed to recognize that the patient was dying and to understand the trade-offs inherent in decisions such as whether to continue life support or to lighten sedation, knowing these may increase suffering. Dr. PallCare was able to connect with the family in a way that helped them to see a new reality and make decisions that were consistent with the patient's goals.

Giving recommendations

When Son2 asked whether the patient would suffer if treatments were removed and what the death would be like, Dr. Fellow2 presented several medical options:

We would probably leave him on the ventilator because...taking him off might make him struggle a bit, or, what we could do is start him on a morphine drip...Or what we could do is up, we could just stop giving him the blood pressure medications...and then just not do anything with the ventilator.

Reflecting on this exchange, Dr. PallCare pointed out that Dr. Fellow2 gave the family too many options and did not really answer Son2's question, which was, "Will he suffer?"

After a brief discussion about code status, Son2 asked about organ donation. After this dialogue, Dr. PallCare redirected

the focus back to the code status making a strong recommendation:

I would do it in steps because it is overwhelming. I would just do the code status first and then talk...I personally believe in good deaths and bad deaths. I think being resuscitated is a horrible death. I think just turning off the blood pressure medicine and then I fall asleep, that's a great way to leave if I'm surrounded by people I care about.

On reflection, Dr. PallCare noted that the family gave clear indications that they had begun to adapt, from talking about wanting to have last words to organ donation. However, the Fellows focused on data, rather than the big picture. Dr. PallCare said in reflection:

Follow the lead of the family. They have come to grips with the fact that he is dying. Then you handle the clinical questions as well as the "Is he suffering?" questions and try to keep the family focused on the big picture. Then you give the family some direction. As opposed to saying, "Well, what do you want to do?" or "Do you want us to do everything?" You have to give them some direction there. That's where I give advice.

Discussion

By providing honest and clear information about the prognosis, focusing on the "big picture," and allowing the family to grapple with the trade-offs, Dr. PallCare improved their capacity to do the adaptive work necessary to make decisions consistent with the patient's goals. By focusing on the adaptive challenges, he gave the family the opportunity to begin to accept a dramatic change in their perception of what they hoped for.

In contrast, the Fellows used technical solutions by presenting the family members with detailed medical information and multiple options. This latter style places the burden of complex medical problem solving on family members, a burden for which most people are unprepared, and ignores the adaptive challenges they face as they try to cope with a new reality.

Several studies have demonstrated high levels of anxiety, depression, and post-traumatic stress in family members of ICU patients.⁷⁻⁹ Family members want to be involved in decision making, but they may not be best served by being placed in the position of having to solve problems for which they lack knowledge and skills.¹⁰ Adaptive Leadership principles allow family members to come to terms with loss and change, to understand the challenges and the necessary trade-offs, and to make decisions that are consistent with the values and the goals of the patient.

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References

1. Billings JA, Block SD: The end-of-life family meeting in intensive care Part III: A guide for structured discussions. *J Palliat Med* 2011;14:1058-1064.
2. Curtis JR: Communicating about end-of-life care with patients and families in the intensive care unit. *Crit Care Clin* 2004;20:363-380, viii.

3. White DB, Braddock CH 3rd, Berekenyi S, Curtis JR: Toward shared decision making at the end of life in intensive care units: Opportunities for improvement. *Arch Intern Med* 2007;167:461–467.
4. Thygeson M, Morrissey L, Ulstad V: Adaptive leadership and the practice of medicine: A complexity-based approach to reframing the doctor-patient relationship. *J Eval Clin Pract* 2010;16:1009–1015.
5. Cilliers P: *Complexity and Postmodernism: Understanding Complex Systems*. New York: The Free Press, 1998.
6. Heifetz R, Grashow and Linsky M: *The Practice of Adaptive Leadership*. Boston: Harvard Business Press, 2009.
7. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenc C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larché J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B; FAMIREA Study Group : Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005;171:987–994.
8. Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, Grassin M, Zittoun R, le Gaul J, Dhinaut JF, Schlemmer B: Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity. *Crit Care Med* 2001;29:1893–1897.
9. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, Curtis JR: Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *Chest* 2010;137:280–287.
10. Frosch DL Kaplan RM: Shared decision making in clinical medicine: Past research and future directions. *Am J Prevent Med* 1999;17:285–294.

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