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Ethics/End of Life

"What if she was your mother?" Toward better responses

Trevor M. Bibler[a,b,*], Susan M. Miller[b]

[a] Baylor College of Medicine, Center for Medical Ethics and Health Policy, 1 Baylor Plaza, Houston, TX 77030, USA
[b] Houston Methodist Hospital, 6550 Fannin St., Houston, TX 77030, USA

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ABSTRACT

Critical care physicians may hear a surrogate decision-maker ask, "What would *you* do if she was *your* mother?" or "What if *your* father was this sick?" These kinds of questions ask more of the critical care physician than the surrogate might realize. There are deep-seated ethical, professional, and personal complexities that can challenge critical care physicians to answer these questions with honesty. This essay offers practical guidance for critical care physicians who aim to respond to such queries with honesty and beneficence. We discuss a variety of motivations that can accompany this unique kind of question from a surrogate. The surrogate may be seeking moral guidance—the true question being, "What should I do?" We offer a number of questions that the critical care physician might ask of the surrogate in order to attend to both the surrogate's moral dilemma and the patient's values and preferences for medical interventions. We also offer a number of questions to promote contemplation of these issues by the critical care physician herself. We argue that until the critical care physician: discovers the surrogate's motivation, connects this motivation to patient preferences, and asks herself important questions regarding death and dying, the physician's responses will not adequately attend to the issues prompted by such questions.

1. Introduction

"What would *you* do if she was *your* mother?" Many critical care professionals have heard surrogate decision-makers ("surrogates") ask similar questions of their ailing parents. Be they referring to their mothers or fathers, these inquiries harbor complex personal, professional, and moral nuance. Responding with a ready-made, reflexive response such as "I wouldn't do this to my mother" (or its opposite) is unlikely to serve the patient or address the surrogate's genuine uncertainty and moral distress. This essay promotes an ethically sound, practical response by recommending a series of questions intended to foster honest and beneficence-based patient care that also heightens the physician's awareness of the surrogate's experience. We will begin by examining common motivations that may prompt the surrogate's question. Following this, we provide questions that may assist the physician in attending to the surrogate's concerns without losing sight of the patient's values and medical preferences. We end with prompts for personal reflection. We contend that physicians who ask *themselves* the kinds of questions the surrogate may be asking *herself* will find it easier to respond with empathy and rectitude as similar questions arise.

2. Motivations

A variety of motivations can influence the surrogate's question. One motivation—perhaps the most common—is that the surrogate is seeking moral guidance regarding a specific medical decision. By asking this question, the surrogate signals that she wants a straightforward recommendation about her loved-one's care. Recommendations for patient care may have been left unsaid or hidden behind prognostic uncertainties when, instead, the surrogate is looking for a concrete plan of care that attends to the patient's values and preferences. If the physician isn't the patient's primary physician, she should arrange for conversation with the primary physician to assist in gaining insights and providing recommendations that attend to the patient's voice and values. If the physician is the primary physician, she should incorporate the preferences discovered during the conversation (see below) into a clear recommendation for future care.

The surrogate may also be looking for another to share in the responsibility of being a decision-maker. This is understandable: the pendulum

* Corresponding author at: Baylor College of Medicine, Center for Medical Ethics and Health Policy, 1 Baylor Plaza, Houston, TX 77030, USA.
E-mail address: bibler@bcm.edu (T.M. Bibler).

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has shifted from good-faith paternalism to families becoming solely responsible for deciding their loved-one's medical fate. Both common sense and recent studies conclude that being a surrogate can be a burdensome, traumatic process [1]. The surrogate is tasked with substantial responsibility, which often produces feelings of powerlessness or even a perception of moral error if the surrogate makes a non-ideal decision.

By asking the titular question, the surrogate may be inviting the physician to share the burden and responsibility for making irreversible medical decisions. A physician confronted with this question should take on this responsibility directly and explicitly, as the surrogate is seeking a shared decision-making model [2]. Shared decision-making here provides a compromise between patient autonomy and medical paternalism [3]; additionally, reducing the anguish of the surrogate is an expression of professional beneficence.

Tone and affect also lend insight into the surrogate's motivations. It is possible that the question is an expression of grief or disappointment, with the surrogate attempting to alleviate stress through venting. The question may be more of an indication of the surrogate's emotional state than an explicit request for guidance or personal connection. Psychological stress can couple with despair to make such a question an expression of existential despair rather than an inquiry into the physician's conception of good medicine. When the need for catharsis motivates the surrogate, the physician might respond by listening with empathy and acknowledging the surrogate's anguish.

3. Questions to ask during the conversation

Since so much medical care is rendered by strangers [4], responding well requires some understanding of both the surrogate and the patient. And while some critical care specialists may be able to combine their experience and intuition into concrete, appropriate responses, being explicit about the essential personal and professional considerations can be of assistance. We divide these prompts into three areas of inquiry, namely, the surrogate's: emotional state, role as a child-surrogate, and decision-making concerns. Regarding the surrogate's emotional state, we suggest asking questions such as:

- How has [your parent's] recent illness affected you?
- What sources of support are available to you?
- Who are you able to talk with?
- Would you like to speak with one of our spiritual care professionals?
- Are you struggling with feelings of guilt, fear, or failure?

The surrogate who poses such a question will likely be struggling with her roles as a child, as a surrogate, or as a part of a larger family [5]. The questions below address the surrogate's relationship with the patient while also reinforcing the importance of making a *surrogate* decision.

- Have others you love been sick before?
- Have you lost others you loved?
- What does it mean for you to be a good daughter/son?
- Are family dynamics affecting your ability to make a good decision?
- Do you have family, spiritual, or professional support in approaching this decision?
- What are you most afraid of?

The third area of inquiry builds upon previous conversation while moving the conversation toward an explicit discussion of the patient's treatment preferences.

- What did a good day look like for her, before she got sick?
- What would you say to your [parent] if she could hear us right now? What would she say to us [6]?
- Are you struggling with reconciling what [the patient] would want with what *you* want?
- Are you experiencing any conflicting opinions on the best course of action?

By addressing these three common areas of concern, the physician will have the opportunity to show genuine investment in the surrogate's struggles while gathering the information necessary to assist the surrogate in answering the titular question for herself. The physician, after all, does not share a parent with the surrogate. She can share in the responsibility for making a shared-medical decision, but there will always be a chasm between the surrogate's lived-experience and the physician's ability to answer such questions [7].

4. Questions to prompt contemplation

We suggest that physicians create some space and devote some time to consider the concerns that undergird the surrogate's question. Unless the physician has considered similar issues, she may be unable to respond in a way that resonates with the surrogate's actual motivations. Indeed, an important goal of this kind of reflection is to make it more likely that the physician's response would be conscientious and consistent with one's professional integrity [8]. We have found three broad themes befitting this mode of purposeful reflection: loss, experiences with illnesses, and one's own end-of-life preferences.

Concerning loss, the following questions may serve to prompt contemplation:

- When have I felt loss and despair?
- When I made a moral or medical mistake, how did I react? What resources were available to help?
- When have I felt moral distress [9]? What resources were available to help?
- Have I ever failed a patient? Were there residual consequences from this failure?

It is also important that the physician consider her past (and future) responses to the illnesses of her parents/loved-ones. One might ask:

- When those I love get sick, how do I respond?
- What did/will I do when my parents/guardians begin getting sick or dying?
- How did/will I balance my professional role with my filial role?
- How did/will I balance being a professional with making a surrogate decision?
- How do I show my love to my family when they are sick?
- How would I want my parent(s) to spend her/his last days or weeks?

The third set of questions is meant to illuminate the physician's personal end-of-life commitments [10]. While a complete accounting of what one holds important is outside this essay's scope, the following questions can begin (or continue) life-long reflection:

- When I begin dying, what will be important for me?
- Who will care for me?
- What signs will show that I have died?
- What does a good day look like now? What might a good day look like as I age or if an illness progresses?
- What interventions am I willing to undergo to possibly get back to these good days?
- Are my religious or spiritual beliefs influencing my end-of-life convictions? If so, how?
- Do my wishes conflict with those of family members or the health care team?

These potential questions are intentionally broad. They are demanding. They create an emotional, as well as a conceptual, resonance between the physician and the surrogate, which can assist the physician in understanding what is at stake for the surrogate. Recall, the surrogate is likely struggling with similar issues and asking herself similar questions. Both the physician and the surrogate will have to accept that incorrect prognostication (for the clinician) [11] and "giving up too soon" (for the surrogate) create tangible moral hazards. Physicians who have reflected in this manner will be more likely to respond to the surrogate's query with attention, empathy, and confidence. Furthermore, these discussions provide an opportunity to create a space for exploring the meaning of life and death [12].

5. Making recommendations

By asking questions, listening for answers, and incorporating the patient's values into a concrete recommendation, the surrogate's specific question (often) dissolves. This resolution occurs because the physician has responded to the most common motivations that generate the question. However, surrogates might return to their question and insist on a direct answer even after the physician has provided virtuous guidance. Simply saying "No, I would not do this to my parent," will not address the surrogate's motivations and concerns. In fact, such an answer ignores the potential for a conversation that connects the physician and the surrogate at the fundamental level the many surrogates are crying out for. However, if the physician has done the challenging work of discerning the surrogate's motivations, inquired into the patient's values and preferences, and seriously contemplated her own ideas on loss and illness, then it is plausible that the physician could answer this question with the nuance required. Responding well should include: an honest description of the physician's relationship with her parent, attention to what is different (and similar) between the physician's parent's and the patient's respective situations, reiterating the physician's recommendation for the path of care the physician believes to be most appropriate, and the explicit recognition that other physicians might answer the question differently because their relationships and experiences differ.

That said, no universal template exists for the physician confronted with such an intimate and complex question. We hope our suggestions offer some structure for introspection—and this introspection leads to professional responses that find harmony between the patient's values, the surrogate's concerns, and the physician's sense of good medicine.

Conflict of interest

Dr. Bibler has no conflicts of interest or financial interests to declare.
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