Virtual Mentor
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Clinical case

The desperate parent and the lure of experimental treatment

Commentary by Peter J. Smith, MD, MA

As a third-year medical student, Alexandra was assigned to a six-week pediatrics clerkship at Hope Hospital, a long-term facility for chronically ill children. She saw this as an opportunity to learn about caring for young patients with incurable illnesses. Hope Hospital was a facility with only 26 inpatient beds, so Alexandra was often familiar with most of the children on the floor. After rounds one day, she decided to stop and visit with Paul, an eight-year-old boy who had been diagnosed with stage IV brain cancer. He was asleep when she entered his room, so rather than disrupt the quiet she took in his room more deeply than she had before, in particular a makeshift altar in one corner.

Parents of patients in the hospital often used counters or tabletops in the hospital rooms to place photographs, unlit candles, get-well cards with inspirational messages, pictures of saints and quotes from the Bible. The biblical quotes in Paul’s room included references to Christ’s miracles, the healing of the deaf, dumb, blind and infirm, and the raising of the dead. Alexandra was reminded that medicine had come nearly to the end of what it could offer Paul; she also remembered Paul’s mother, an older parent, who had lost another son—her only other child—to brain cancer. She was now left with a slender hope; she had opted to enroll Paul in the latest, experimental drug trial from the NIH.

The physicians at the hospital were not convinced that Paul had the reserves of strength to withstand additional chemotherapy or radiation and had suggested to his mother that treatment for his cancer be discontinued. But any mention of moving to palliative care or hospice was rebuffed by Paul's mother. If a new drug was being tested, she insisted that Paul be included in the trial. When Alexandra turned to leave the hospital room, Paul’s mother entered, smiling as always. Alexandra smiled in turn. The two had talked often over the weeks of Paul’s hospitalization. Alexandra acknowledged that Paul was scheduled for further chemotherapy, to which Paul’s mother replied, “Wouldn’t you do the same? What’s your honest opinion, Alexandra?”

Commentary

“Doctor, if he were your child, what would you do?” In 1999, using this question (likely as old as medicine itself), Robert Truog wrote a classic article that has stimulated an important literature within bioethics on the role that personal beliefs and opinions ought to play when clinicians counsel families. He argued that pediatricians ought *not* to answer this question, using an example from psychotherapy to make the point that physicians are *not* the experts in values, that they are experts in "medical facts":

> Complete objectivity is impossible between a physician and parent when discussing value-laden questions like whether to withdraw life support. Countertransference is the general term for describing the beliefs, prejudices, and feelings that the clinician brings to the discussion. Just as a good therapist would rarely, if ever, give a direct answer to the question, "Now tell me doctor, if you were me, would you divorce my wife?" so should pediatricians be reluctant to provide direct answers to similarly profound questions from parents. The job of the clinician in this case is to guide the patient or parent to a choice that is authentic and genuine for them [1].

A group of important commentaries responding to the original article by Ross, Ruddick, Halpern, Quist and a reprise by Truog [2-6] were published together and, as a group, serve as a useful primer for any learners wishing to acquaint themselves with the important points under debate. Learners will also benefit from noting that the discussion continues (and will likely continue indefinitely), as witnessed by the perspective on this question offered recently by Kon [7]. However, the discussion is usually framed with the understanding that the health care professional who is asked the question is both a real decision maker (or at least has strong influence in the outcome of the medical teams' group opinion) and an experienced clinician. This commentary will attempt to address the question with particular reference to a caregiver who is neither the ultimate decision maker nor truly experienced in the practice of medicine: Alexandra is a medical student, and that makes all the difference.

Medical education and core competencies

Learning the art and science of health care is a long and arduous process. During training, novices are frequently confronted with difficult questions from the patients and families they serve. Unfortunately, these experiences are often characterized as opportunities to "learn the right thing to do." Currently, an educational model is in the ascendancy that mandates teaching of well-defined core competencies: patient care, medical knowledge, interpersonal and communication skills, professionalism, practice-based learning and improvement, and systems-based practice—and measuring the effectiveness of this teaching [8, 9]. The movement which stimulated the rise of this model has many positive aspects, especially the drive towards valuing medical education *as* education rather than as a source of labor for teaching hospitals where students and residents learn from older physicians who usually are not trained in teaching or understanding the needs of the learner.

This movement has, however, also fostered an atmosphere in which training increasingly focuses upon content, standardized tests or—potentially worse—

standardized patients, “objectively” measurable outcomes and generally anything that can be quantified. This has led, in turn, to an increasingly common attitude that there are right and wrong answers to all questions, problems and choices of action in a situation. Therefore, it is quite possible that Alexandra’s greatest anxiety was related to her ability (or inability) to remember what she was supposed to have learned in the mandatory session on “cultural competency” that certainly preceded her clinical rotations. She and her clinical supervisor will surely need to complete an evaluation at the end of this rotation, at which time Alexandra will receive appropriately constructed and delivered feedback. Part of that evaluation will attempt to measure her knowledge and skills in this area.

Alas, I suspect that anyone who has not attended medical school would hope that Alexandra’s greatest anxiety would arise from her desire to learn how best to be compassionate toward a very vulnerable fellow human in this situation. Alexandra herself may have hoped to learn that (and may have written an essay about just that worry on her medical school applications) prior to her immersion in the world of medical education.

Clearly, those who create courses in cultural sensitivity, no matter how well done and how highly rated, will not be able to adequately prepare their students for the infinitely varied and tremendously complex experiences they will confront. They often do give good advice on what *not* to do. However, because they need to utilize generalities—they are teaching a varied group of students to serve a multicultural society—they usually do not attempt to answer Alexandra’s problem, “what *ought* she to do?”

Virtue ethics

One answer to this problem may be found in looking to a different and ancient paradigm of constructing ethical exchanges and deliberations: virtue-based ethics. Contemporary virtue ethicists often specifically define themselves as *not* attempting to create systems that promote virtuous *actions*. For one example, see Edmund Pellegrino’s “The Virtuous Physician” [10]. These ethicists do not spend the majority of their energies on debating the “right thing” to do in a circumstance. (Note that they do *not* believe that it is a *bad* idea to try to work out the right thing to do, and for examples of good forms of this principle-based model, see the articles referenced at the top by Truog and those who responded to him.) Rather, virtue ethicists focus upon creating environments and expectations that help foster the formation of virtuous *character*. As James Keenan, another virtue ethicist, writes:

> Renewed interest in virtue ethics arises from a dissatisfaction with the way we do ethics today. Most discussions about ethics today consider major controversial actions... .Virtue ethicists are different. We are not primarily interested in particular actions. We do not ask, “Is this action right?” “What are the circumstances around an action?” Or, “What are the consequences of an action?” We are simply interested in persons. We believe that the real discussion of

> ethics is not the question "What should I do" but "Who should I become?" In fact, virtue ethicists expand that question into three key, related ones: "Who am I?" "Who ought I to become?" "How am I to get there" [11]?

A virtue ethicist would view this clinical encounter not as a dilemma in which it is hard to know what to do but as a part of the formation of Alexandra's character. Therefore, a virtue ethicist would hope that Alexandra had seen many good models of compassion (from the Latin "to suffer with"), especially at this facility which specializes in the care of children with complex and chronic conditions. The examples might not have all been doctors, but Alexandra might have been astute enough to learn from among *all* the humans in the institution. A virtue ethicist would hope that Alexandra's training had included a message to watch *all* the care given to the children served at this special place. Finally, a virtue ethicist would hope that Alexandra would follow her heart and try to say something humane and humble and loving.

It is likely that Alexandra would feel awkward and uncomfortable and inadequate (just like a seasoned clinician, though she would not yet know that these feelings never fully go away), so a virtue ethicist would hope that she would have a chance to share her understanding of the experience with a seasoned, caring and wise mentor. Although there are many ways that a mentor would help Alexandra, one way would be to explore her feelings and thoughts about the experience as they relate to the three questions posed by Keenan: "Who am I?" "Who ought I to become?" "How am I to get there?" A mentor might reassure her that formalized processes are only useful as a stimulant to this type of self-reflection (which may lead to improved self-understanding). A good mentor would most certainly *not* believe that there is one right thing that an ethical person would or should say to Paul's mother in this narrative and might try to help Alexandra to see this truth. Alexandra's growth and the fostering of her attitude of compassion would be the ultimate goal of a virtue ethicist.

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