Ethics Dispatch

"The object of philosophy is the logical clarification of thoughts. Philosophy is not a theory but an activity."

- Ludwig Wittgenstein

Hot Topic: From Oncology Nurse to Oncology Patient

We sometimes distinguish between the world of medical providers and the world of patients. The world of medical providers may involve engaging patients, offering diagnoses, discussing relevant treatment options, referrals, recording information in the EMR and collaborations with other medical providers. The world of patients, on the other hand, involves filling out paperwork, scheduling appointments, receiving care, visits to the pharmacy, and working with healthcare insurance agencies to coordinate and finance care. In short: the world of the medical provider represents a world of those "who care," while the world of the patient represents a world of those who are "cared for."

These two worlds get fused together in a recent article by a veteran oncology nurse, Theresa Brown, who recounts her experiences navigating the healthcare system as a patient. Theresa was diagnosed with breast cancer and experienced first-hand what the patient world was like. In the article, she mentions feeling taken aback by the fact that little effort was done to "coordinate" her care or make her feel like her medical team was "taking care of things," despite being diagnosed with a very common and treatable breast cancer. During her treatment, she notes longing for "warmth and kindness," but instead being treated as a passive item on an assembly-line:

"As practitioners, we also give out the message to patients to be passive and undemanding — and patients absorb it. Health care is like an assembly line, and not just one. There's the breast cancer assembly line, the billing assembly line and the let's-get-people-in-and-out-of-here-as-quickly-as-possible assembly line. When you put the brake on one of those assembly lines, it messes with everything because everybody is overworked and everything is over-scheduled."

It bears mentioning that not all medical providers treat patients like passive items on a conveyor belt. Probably most demonstrably strive to promote

empathy and care in their practice. Notwithstanding, Theresa's experiences as a cancer patient underscore various issues about the patient world and the provider world, and their intersection.

One issue stands out in particular: the role of care in medical practice. In a New York Times article, Theresa Brown notes arriving at the following realization: "I had not understood that indifference can become a form of cruelty when one's life could be at stake." This realization came shortly after a frustrating experience navigating the medical system. After receiving worrying results from a mammogram, Theresa tried scheduling a biopsy with a receptionist. She was informed by another receptionist that the scheduling receptionist left early and that she "just missed her." The scheduler's seemingly minor misstep filled Theresa with rage. The journalist writes of Theresa's recollection:

"She later realized that her bursts of anger stemmed from a helplessness she felt over her disease, a desperation she failed to recognize often enough in her own patients in the oncology ward and as a home hospice nurse."

In her anger, helplessness, and desperation, Theresa experienced the world as both an oncology nurse and oncology patient. "It was like a breaking of trust right in that moment and I felt like I worked really hard to have patients trust me," she writes.

These reflections invite a number of questions about the patient-provider world. For starters, what can healthcare providers, schedulers too, learn from the patient world--from our own personal experiences as patients, but from other patients also? How can this knowledge be accessed and applied in contexts of care? Do healthcare professionals have a moral obligation to be caring *toward* their patients, to care *for* them, in addition to providing care?

Bioethics in the News

Supreme Court Overturns Roe v. Wade
Why Bioethics Needs Pride
Structural Racism in Health Care
Ethics Consult: Cut Health Insurance for Risky Activities?

Case Study

Collin is an APRN in the ICU.

Collin is part of a medical team caring for a 27-year-old male identifying patient named Xiang who sustained numerous injuries from a car accident. Xiang is

stable, has full decisional capacity, but suffered extensive trauma to his leg. According to his medical team, the trauma is so severe, leg reconstruction is likely impossible, short of some miracle. They agree it is best to amputate the leg, below the knee (BKA).

The medical team meets with Xiang, who is accompanied by his mother, to discuss his situation in depth. After delivering the news, the medical team leaves, but Collin stays behind to check on Xiang and his mother.
Xiang's mother, a devout Christian, believes that Collin should "put everything in God's hands." "My son does not need an amputation. God will restore his leg. The doctors will see. We are praying for a miracle." Xiang agrees emphatically with his mother, further noting his family's bad experiences with hospitals and doctors elsewhere when healthcare had been needed. So Xiang, while expressing gratitude for the care provided here, has decided to place his trust "in a higher power."

Collin takes a moment to further underscore the complications and consequences that may arise from not having the leg amputated, including death, but it appears Xiang has made up his mind.
Confused and concerned, Collin leaves Xiang's room. He wants to provide "the best care possible," per the mission statement of this healthcare system, also. But what does one do when a patient decides to decline our "best care" while trusting God for miraculous healing instead? What does "care" mean in a situation like this?

Time is of the essence, as Xiang's physicians had explained to their patient. If Xiang does not consent to a BKA, his prognosis for recovery goes from excellent to uncertain, or worse. Necrosis is nearly certain for lack of sufficient blood flow to the lower leg. Despite excellent infection control measures here, sepsis will happen sooner or later, with a potentially fatal outcome. Xiang's pain could be severe, mitigated only by deep sedation at best. This might turn out to be a horrific death of a young man, a death wholly preventable.

While imagining the worst-case scenario, Collin believes there might still be hope for negotiating a reasonable care plan. In their team huddle that afternoon, Collin conveys his worries for Xiang. He suggests that they request an ethics consultation.

Ethical Musings: The Ethics of Care

By many accounts, the nature of ethics is to evaluate human action. Theories of ethics, then, tell us which actions are morally permissible, morally required, or morally impermissible. In the words of T.M. Scanlon, evaluating whether an

action is “right” or “wrong” is fundamental when addressing “what we owe to each other.”

The ethics of care, or Care Ethics, has a different focus, one that emphasizes human relationships over human actions. According to one of Care Ethics’ main proponents, Nel Noddings, this theory emphasizes “the recognition of needs” and also “the maintaining and enhancing of positive relations.” She characterizes her view as follows:

"An ethic of care—a needs- and response-based ethic—challenges many premises of traditional ethics and moral education. First, there is the difference of focus already mentioned. There is also a rejection of universalizability... Universalizability suggests that who we are, to whom we are related, and how we are situated should have nothing to do with our moral decision making. An ethic of caring rejects this... Although it calls on people to be carers and to develop the virtues and capacities to care, it does not regard caring solely as an individual attribute. It recognizes the part played by the cared-for. It is an ethic of relation."

In other words, Care Ethics maintains that relationships matter to moral reasoning, and that care is fundamental to building and maintaining relationships. The insight here is that we all bear some care relationship to another, be it in the capacity of father-daughter, son-mother, sibling-sibling, friend-friend, or grandson-grandfather. The world of those “cared-for” is morally significant to the world of those who “care,” and vice versa.

How do insights from Care Ethics bear on the case of Collin and Xiang, or that of Theresa Brown? In navigating the healthcare system, Theresa not only experienced the world as a cancer patient, but the world as a cancer patient with *needs*, inclusive of the need for positive relationships with those providing healthcare. She recounts her experiences:

"Why don’t they give out a sheet that says this is what you have and this is what the prognosis looks like? Nobody gave me anything in writing like that. Nobody ever said, “We’ve got this. This is the most common kind of breast cancer. We know how to treat this. You are going to be OK.” That would have made it so much better able to tolerate things."

From a Care Ethics perspective, the relational needs of a patient are fundamental to moral decision-making with them or on their behalf. To better navigate the world as a cancer patient, Theresa needs her medical providers to inform her with greater care about her diagnosis and prognosis. As a patient with cancer, she needs providers to convey with care the likely effectiveness of the recommended treatment plan. She needs a receptionist to understand that

scheduling an appointment, while trivial for the scheduler--a repetitive action done dozens of times daily--is highly significant for each individual patient. Even schedulers (perhaps especially schedulers, given Theresa Brown's experience), need to care. Each of Theresa's needs as a cancer patient are morally significant, and meeting those needs in a caring fashion can help build a positive patient-provider relationship for better healing.

Viewing Xiang's case through the lens of Care Ethics, and if responding in the role of ethics consultant, we might note the unique care-provider relationship that the patient's advanced practice nurse fulfills for Xiang and his mother. Collin is the one who cares enough to stay longer at the bedside, to listen deeply, carefully, to both the patient and his family care-giver. Collin cares enough to restate the care team's strong recommendations and rationale for what Xiang needs from a medical perspective. The nurse cares sufficiently to worry when those recommendations are declined for an unlikely miraculous option and on grounds that seem unwise if also understandable given less than-ideal experiences with healthcare elsewhere.

In future bedside visits, Collin or other caregivers could elicit from Xiang and his mother the stories they might tell about healthcare that was experienced as uncaring. Hearing carefully those experiences may result in assessment of the care in this facility, leading to quality improvement measures. In the process, this patient and family will feel respected. Trust may be enhanced even such that healthcare recommendations ultimately are accepted rather than rejected. Listening carefully can lead to a better understanding of the patient's psychosocial needs, some of which could impinge upon a decision for or against recommended medical care, including the BKA.

Collin demonstrates caring for his patient when bringing his concerns back to the team huddle, and when requesting ethics help via consultation. That consultation might elicit other needs of the patient for which a caring response is warranted--even if a life-saving intervention continues to be declined on religious or other grounds. Care Ethics calls us to respectfully care even when our efforts to provide the medically "best care possible" are thwarted by an autonomous patient's decision AMA (against medical advice).

- By Polo Camacho, PhD and Terry Rosell, PhD, DMin