Healing without Curing: Ethical Reflections on Palliative Care Medicine

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HEALING WITHOUT CURING: **ETHICAL REFLECTIONS ON PALLIATIVE CARE MEDICINE**

INTRODUCTION

For palliative care medicine (PCM), “home is where the hurt is.” This interdisciplinary team of clinicians – a senior attending physician, a nurse practitioner, a social worker, and a chaplain – each with extensive palliative care training – begins each day in a new place. Their patients, debilitated by diseases that elude medical remedy, are quiet, solemn, and too often alone. Many are homeless, others poor, and, others rich in every sense but health. The complexity of this patient population is unlike any other.

Decision making in PCM is rather unique. While the majority of patients possess the capacity to make their own health care decisions, many must do so in light of their impending death. As such, palliative care serves as the singular clinical service that invites patients, from the very beginning, to actively participate in their *own* end-of-life decision making. Few individuals in contemporary society have imagined the sort of clinical care they might want come the evening of life. Still, less have shared this information with others, giving them the ability to carry out their wishes “when the time comes.” Yet, this is precisely the situation into which one is tenderly forced in the context of palliative care. From the very beginning, “the time” has come. That is, patients act, in the present, to make those very decisions, according to their own values. They possess full control of their fate. They actively will determine the manner in which they die – an almost divine phenomenon.

HOPING AGAINST HOPE

End-of-life decisions are perhaps the most common and difficult problems confronting patients, clinicians, and bioethicists in healthcare. Particularly in the evening of life, conflicts about care often have multiple causes. Patients, surrogates, and even clinicians may not understand the capabilities or limitations of contemporary medical technology, and so may base decisions on false information. Due to the debilitating nature of guilt, grief, fear, denial, and suspicion, patients and surrogates may refuse to accept the fact that further intervention promises no more benefit than burden. Because of the disparateness of beliefs, attitudes, and values between patients, surrogates, and clinicians, each may engender a different notion of the good in relation to care at the end of life. In a unique way, PCM challenges the bioethicist to familiarize himself/herself with the treatment options, the common dilemmas in sorting through them, and practical, compassionate approaches to analyze and resolve them.

Determining the quality of life for individuals who no longer possess biological hope of recovery is an idiosyncratic task. The patients themselves must make it – a burdensome, if excruciating, onus. It’s one thing to muster the strength necessary to make medical decisions for an incapacitated other; it’s quite another to make them for oneself, as one slowly deteriorates and pain shifts from persistent to profound. Through introducing the notion that relieving pain and suffering is essential to the continued care of the individual, palliative care proves critical to the moral endeavor to preserve patient dignity while maintaining medical responsibility.

FROM CURING TO CARING (AGAIN)

Proving comfort, particularly at the end of life, is hardly a departure from the traditional moral responsibilities of medicine. Until the middle of the twentieth century, the cure of disease and the prevention of death were beyond the reach of clinicians who cared for the terminally ill by attempting to relieve pain. With the birth of biotechnology, the obligation to provide care morphed into the obligation to provide cures. As such, the focus on comfort was displaced, reserved for those times when curative measures fell short and “nothing more can be done.” Rather than a biological inevitability, death came to be viewed as a failure – a failure of technology, a failure of clinical skill, and, perhaps worst of all, a failure of patients to “beat the odds.” This major increase in scientific technology would falsely inflate both individual and collective expectations of the power and role of medicine.

“The old medical mentality had to go. It was time to open the windows, get some fresh air, and realize our limitations. People perish, and that’s alright. It doesn’t mark failure; it marks humanity.” Dr. D.’s remarks were encouraging to me. She was not fooled by the capabilities of modern biotechnology. She undoubtedly respected it. Indeed, she admired it. But she realized something most clinicians fail to: the fragility of the human person. “This was not a lesson I learned from textbooks; I learned it from accompanying people in the final days of their lives, and offering them hope – not of recovery, but of meaningfulness.” The meaningfulness of which Dr. D. spoke all week was poetic. She didn’t attempt to cure the existential wounds of her patients. Rather, she promised to be present in her patient’s experience of them. “For them,” she added, “that is usually enough to heal.”

MORAL OF THE STORY

Beyond being a clinical obligation, time and energy dedicated to the relief of pain remains a moral imperative. Yet, pain persists as a complex phenomenon for which there is no uniform solution. In multiple ways, pain serves as a pressing notion and experience for both clinicians and patients. First, pain is a subjective, solitary experience. Unlike other indications of illness or injury (e.g., the presence of infection or difficulty breathing), information about pain is available to the clinicians only through the patient’s description of and response to it. Second, the experience and understanding of pain is influenced as much by idiosyncratic values and cultural traditions as by physiological injury or disease. As such, the way pain is experienced and expressed by the patient and how it is interpreted by the clinician largely determine how it is valued and, ultimately, treated. Finally, both patients and clinicians are influenced by their respective understandings of pain and its proper remedy. Studies indicate that clinicians are reluctant to provide adequate analgesia due to lack of education, concerns regarding addictive properties, and fears about legal liability.

Over the course of this hectic week, the dying would teach me much about living. The compassion with which the members of the palliative care team met each patient was truly inspiring – something I will not soon forget. The humanity of medicine was laid bare. Meaning shined forth. And, for the first time in two weeks, I felt personally connected to each patient I encountered. I held their hands differently. I spoke slower, and with more intention. I entered into their chaos and asked for the opportunity to accompany them in the final chapter of their

lives. And they couldn't have been happier to accept it. Working alongside PCM reminded me of a primary duty in bioethics: to first go where the pain is, and to accompany the individual who suffers it. To travel into the darkest corners of life with patients, and from there, to navigate without getting lost.