

Humanities: Art, Language, and Spirituality in Health Care

Series Editors: Christina M. Puchalski, MD, MS, and Charles G. Sasser, MD

Rethinking Hopelessness and the Role of Spiritual Care When Cure Is No Longer an Option

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Abstract

Increasingly in the U.S., health care clinicians fail to recognize and accept when curative goals are no longer realistic. At this point, futile efforts at cure can fuel false hopes in patients and their loved ones. The clinician's need to be "doing something" may result in treatment that violates the dignity and well-being of the patient and this can lead to the patient's ultimate hopelessness and despair. This article uses a personal narrative to explore the hopelessness of a patient diagnosed with nonresectable pancreatic cancer and the challenge it raised for the author, who was a friend and a nurse to the patient. Hope is described as a virtue that takes as its object "a future good, difficult but possible to obtain," and that sits squarely between false hopes and despair. Spiritual care that addresses three universal spiritual needs (meaning and purpose, love and relatedness, and forgiveness) is recommended as a valuable intervention to address hopelessness. J Pain Symptom Manage 2012;44:626–630. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Introduction

"What should medicine do when it cannot save your life?" queries Gawande,¹ a surgeon, writer, and public health researcher, in a seminal article entitled "Letting Go," which was published in *The New Yorker* in 2010. Gawande contrasts the popularity of guides to the art

of dying (*ars moriende*) in the 15th century when people accepted the inevitability of death and the need to prepare to die with the realities of today's U.S. death denying culture.

These days, swift catastrophic illness is the exception; for most people, death comes only after long medical struggle with an incurable condition—advanced cancer, progressive organ failure, or the multiple debilities of very old age. In all such cases, death is certain, but the timing isn't. So everyone struggles with this uncertainty—with how, and when, to accept that the battle is lost. ...Besides,

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how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are? Is someone with terminal cancer, dementia, incurable congestive heart failure dying, exactly?¹

I want to address the increasing tendency of health care professionals to obfuscate knowing and accepting that the battle to overcome death is lost by restricting attention to discrete pathologies, infection, renal failure, decreasing cardiac ejection fractions, with discrete interventions, antibiotics, dialysis, inotropic drugs, and ventricular assist devices—often at the expense of the person, his/her dignity, and quality of life. By promoting false hopes of cure, health care professionals rob the seriously ill and dying of the timely opportunity to prepare for death, and this paradoxically often results in end states of despair and hopelessness for both patients and their loved ones. I believe that we can do better as professional caregivers but it will take a radical rethinking of the ends of medicine. Should good dying as an end of medicine be restricted to hospice professionals or rather be a legitimate goal of all who care for the seriously ill and dying? Similarly, if good dying is an outcome that obligates all who care for the seriously ill and dying, we need to question how skilled professional caregivers are when identifying and meeting noncurative goals. I begin with a narrative that issued a personal challenge to my clinical competence, and will focus specifically on hopelessness and spiritual care interventions to address such hopelessness.

Jim's Challenge

Jim was a close friend who, at the age of 36 years, was diagnosed with advanced nonresectable pancreatic cancer. I was at his bedside several days postoperatively when his oncologist arrived to talk about his treatment options. Having taught medical student classes on “breaking bad news,” I was delighted to discover the oncologist following almost all of the best practice “rules” for delivering bad news. He sat down at the bedside, chatted a bit with Jim to get a sense of his level of education and familiarity with medical care, and honestly reported that this was a serious cancer

and one with a mean survival time of six to seven months—but then pulled a Valentine's card out of his breast pocket that was sent from a patient diagnosed with the cancer seven years earlier. He described the standard treatment option of chemotherapy and radiation but raised my curiosity when he seemed to be in no rush to start treatment. He counseled Jim to go home, rebuild his strength, and when ready, to schedule an appointment to talk about treatment. What the oncologist did not do was to include as an option transitioning to purely palliative goals. When I spoke with oncology colleagues, I learned that although the proposed treatment was the standard option, it was not extending survival time. Patients felt like “something curative was being done,” but often suffered the adverse effects of chemotherapy and radiation without concomitant therapeutic benefits. I then had a serious conversation with Jim about another alternative that I tried to couch in scientific terms. I suggested that going home, using each day's energies to do the things that mattered most to him, and eating what he wanted to eat might just boost his immune response and be at least as effective as chemotherapy and radiation. Jim was living with his mother at the time. I was distressed to receive a call from Jim's mother two days later sharing how disappointed Jim was that I suggested “doing nothing” because it meant that I was “giving up hope.” For the first time in my professional practice, I was forced to ask myself what I had in my clinical armamentarium to offer an individual for whom cure was no longer a realistic option. As an experienced nurse, a woman of deep faith (a Catholic sister), and a health care ethicist, I was chagrined to realize that, until this moment, this had never been a matter of serious reflection for me.

A quick exercise of our imaginations will reveal the importance of hope for the seriously ill and dying. Imagine if you would that you discovered a lump in your breast or scrotum this morning while showering. What is your first hope? Most likely you hope that it is benign, not malignant, and nothing to worry about. But should you get the lump biopsied and discover that it is a cancerous lesion, your next hope would probably be that it responds to treatment. Now imagine that you have unsuccessfully tried all treatments—even a research

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