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.

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Hopelessness, despair, spiritual care

Introduction
“What should medicine do when it cannot save your life?” queries Gawande, 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,
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, ionotropic 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
protocol—and your physician tells you, “There is nothing more medically we can do to attempt cure.” At this point, the most telling question becomes, “What is the source of your hope?” Although most health care professionals and companions of the seriously ill and dying are skilled in keeping hope for a medical or miraculous cure alive, we are painfully inept in helping them discover sources of meaning when death is imminent. In what follows, I will define hope, explore interventions to address hopelessness, and attempt to situate this in the broader context of spiritual care.

Hope Defined and Measured

According to Thomas Aquinas, hope is a virtue that takes as its object “a future good, difficult but possible to obtain.” As such, it allows us in times when we are acutely aware of our limitations and finitude as humans to move beyond them. Nurse researcher Kaye Herth, developer of the Herth Hope Index, identified three factors of hope: inner sense of temporality and future (presence of goals, positive outlook on life, and seeing potential in each day), inner positive readiness and expectancy (sense of direction, believing life has value and worth, and seeing a light in a tunnel), and interconnectedness with self and others (faith that comforts, deep inner strength, and giving and receiving care and love).

Morse and Doberneck developed a conceptual framework regarding the process of developing hope in response to a threat, which includes seven universal components:

1. A realistic assessment of the predicament or threat;
2. The envisioning of alternatives and the setting of goals;
3. A bracing for negative outcomes;
4. A realistic assessment of personal and external resources;
5. The solicitation of mutually supportive relationships;
6. The continuous evaluation for signs that reinforce the selected goals; and
7. A determination to persevere.

J. Donald Schumacher, president and chief executive officer of the National Hospice and Palliative Care Organization, identifies six circles of hope for the terminally ill that have an ever-narrowing focus of identification:

1. Hope for a cure;
2. Hope for a sudden and long remission of disease;
3. Hope for a pain-free existence;
4. Hope for the resolution of interpersonal relationships;
5. Hope for self-forgiveness; and
6. Hope to be remembered well.

Ted Creen, a pastor in Canada, speaks of hope as developing from the basic human need to achieve or create.

At its root, hope embodies the question of the essence of ourselves that will live on after we die, our contribution. The power of this need fuels our will to live: the loss of such a drive leads to feelings of helplessness and despair. …Hope is the ingredient in life that enables an individual both to consider a future and to actively bring that future into being. …Hope has the capacity to embrace the reality of the individual’s suffering without escaping from it (false hope) or being suffocated by it (despair, helplessness, hopelessness).

For the individual with a serious illness who realizes that life may be shorter rather than longer, the question of the future no longer in the here and now is concrete and real. Developmental theorist Erik Erikson identifies ego integrity vs. despair as the last developmental stage. I like to think about this in the light of the account of creation in the Book of Genesis. After each day of creation, God looks at what was created and states, “This is good.” Close to death, I need to be able to look at the life I’ve created and say, “This is good,” if I want to know deep peace and hope for the future. It is no surprise that many contemplating the end of life as we know it are afraid for a future they cannot begin to imagine. Helping the seriously ill and dying to repair their relationships harmed over a lifetime can promote peace and the ability to look to the future with anticipation.

My friend Jim had struggled with alcoholism during his entire adult life. Raised Catholic, he had stopped going to church when he was in college, and at the time of his cancer diagnosis he found no comfort or support in
a relationship with God or a higher power. Moreover, he had alienated friends and even family. Death was a frightening prospect. On the continuum between ego integrity and despair, he was solidly in the despair category. Could I be available to Jim in a way that promoted his healing? What did our tradition of spiritual care have to offer to Jim and to me?

**Spiritual Care**

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. In the words of theologian Karl Rahner, spirituality is:

> simply the ultimate depth of everything spiritual creatures do when they realize themselves—when they laugh or cry, accept responsibility, love, live and die, stand up for truth, break out of preoccupation with themselves to help the neighbor, hope against hope, cheerfully refuse to be embittered by the stupidity of daily life, keep silent, not so that evil festers in their hearts, but so that it dies there—when, in a word, they live as they would like to live in opposition to selfishness and to the despair that always assails us.

For the seriously ill and dying—for Jim—the work of “realizing oneself” can be a tough challenge, especially when attempted alone. Physician philosopher Dan Sulmasy writes that in the final analysis, every dying person who retains the capacity to hear and to understand the call of death faces two important sets of questions: questions of value and questions of meaning.

...The first set of questions relates to value. At some level, the dying person must ask questions such as the following: Do I, as an embodied person, have any meaning here and now? Has my life, as I have lived it until now, had any meaning? Has there been any meaning in what I have suffered? Will there be any meaning in my living and dying that perdures beyond the moment of my death. Questions of value have been subsumed under the word *dignity*; questions of meaning have been subsumed under the word *hope*.

We can all probably think of individuals who have expressed questions of meaning and value at the end of life—but it is the rare professional caregiver who is skilled in eliciting these questions in the context of a patient history and assessment and equally skilled in addressing them.

Healing may be described as a gradual awakening to a deeper sense of self (and of the self in relation to others) in a way that effects profound change and integration. Healing comes from within and is consistent with a person’s own readiness to grow and to change. A healing attitude is:

> a belief system that recognizes that all of life’s experiences, including injury, illness, and other setbacks, provides us with opportunities to learn and to grow toward that we are meant to be. Seen in this light, disease is not an enemy but a teacher and motivation. Disease is manifesting, in a physical way, the desire or need of the psyche to reestablish balance and integration through a change of direction in one’s lifestyle, behavior, or attitudes.

Defined simply, healing is the integration of self. People move from a sense of brokenness to a sense of wholeness. Proponents of holistic health are oriented to wholeness of being, not simply wholeness of body. They recognize that cure is only one of the forms that healing can take. I may neither be able to “cure” all disease nor “fix” all problems associated with aging, chronic illness, dying, and death, but I can journey with those suffering these existential challenges and help them become more integrated, authentic, and whole not in spite of these realities but because of them.

As I thought about how I could best journey with Jim, I remembered nurses Fish and Shelly describing three spiritual needs underlying all religious traditions and common to all people:
1) need for meaning and purpose, 2) need for love and relatedness, and 3) need for forgiveness. Spiritual care can be defined most simply as care that enables individuals to meet these basic spiritual needs. I spoke with Jim about these needs and said that he was fortunate to have the time to work on meeting them—unlike folks who die suddenly. I recounted the story of Dame Cecily Saunders who surprised listeners by saying she hoped that she would die of cancer because it would give her time to say, “Thank you, I’m sorry, Good-bye.” I added that I would want to include, “I love you” in my last messages. By remaining respectfully present to Jim, I tried nonverbally to affirm my conviction that Jim and all humans have at their core a divine spirit—one that loves great desires in us. With the urgency of knowing that death will come sooner rather than later, we can direct our hopes to unconditional healing and forgiving love.

Jim rejected chemotherapy and radiation and lived for almost two years after his diagnosis. His funeral was well attended by family and friends—many of whom remarked on what a blessing his last years were. He mended numerous relationships and died peacefully in his sleep. Jim’s gift to me was a new appreciation for the universal spiritual needs that make every human simultaneously vulnerable and resourceful. My inability to cure Jim’s cancer opened a new role for me as a faithful companion as he journeyed through despair to healing and wholeness. Health care professionals who value spiritual care always have something to offer the seriously ill and dying.

Spiritual care models offer a framework for health care professionals to connect with their patients; listen to their fears, dreams and pain; collaborate with their patients as partners in their care; and provide, through the therapeutic relationship, an opportunity for healing. Healing is distinguished from cure in this context. It refers to the ability of a person to find solace, comfort, connection, meaning, and purpose in the midst of suffering, disarray, and pain. The care is rooted in spirituality using compassion, hopefulness, and the recognition that, although a person’s life may be limited or no longer socially productive, it remains full of possibility.

References
2. Aquinas T. Summa theologica, II-II, q. 17, art. 1.