

OFFERING A FLICKERING LIGHT

How Caregivers Contribute to Atmospheres of Hope

Hope is reflected beautifully at the beginning of chapter three of Ecclesiastes: For everything there is a season, a time for every affair under the heavens. It is here that we see how all people and things are created in a way that connects them with everyone and everything else. This interconnectedness gives meaning and purpose to the circumstances of our lives; meaning and purpose serve as sources of hope. Reciprocally, hope helps us find that meaning and purpose. Each season and time provides an opportunity for growth in the spiritual dimension of life, and hope is there as a great helper. In the Christian tradition, we know hope as a theological virtue.

My interest in the topic of hope stems from my early years as a nurse and my life as a Sister of Providence. Our mission calls us to “bring a sign of hope” to the poor, the sick and aged. As a nurse, I heard patients, families and staff talk about their hope and hopes. I saw hope in action. I focused my doctoral dissertation on hope of elderly patients with advanced cancer.¹ During a two-year period, I interacted with 35 patients from diagnosis to death. Since then, I have followed the growing body of literature and research from many disciplines. In each of my ministry roles, I have observed the hoping processes of patients, families, caregivers, health care executives and even boards of directors.

As people entrusted with the care of our sick, frail and otherwise vulnerable brothers and sisters, we need to understand what supports patients’ hope so that we, as caregivers, can be counted among their sources of hope.

Hope is a dynamic life force characterized by a confident, yet uncertain expectation of good, which to the hoping person is personally significant and is realistically possible. Hope energizes one to action and has implications for interpersonal relationships with others, both living and

dead, and with God and other living beings. It is most active within the context of actual or potential loss and suffering.²

Hope may be linked to particular objects of hope. Equally important, hope includes a general sense that the future will bring beneficial but indeterminate developments. Hope could be likened to an intangible umbrella or parachute that protects the hoping person. Hope filters some semblance of a positive glow upon life deeper than mere optimism. It imparts an overall motivation to carry on with life’s responsibilities amid hardship and gives a broad perspective for life and thought. We hear people with advanced illness say:

- Hope keeps me going. It’s an outlook that makes sense of things.
- I’ve always lived by a spirit of hope. If you give it your best and trust, things do work out.
- I just hope, that’s all. I don’t hope for anything in particular at this point, because I’m not sure what to hope for with my condition changing so fast.
- I won’t tie God’s hands by being too specific in my hoping and praying.

SOURCES OF HOPE

Sources of hope can be concrete or abstract, time-limited or enduring. Sources of hope are persons, things or conditions that give rise to hope or influence the hoping person. They provide grounds and occasions for hope. Sources of hope instill, maintain, support, reinforce, maximize, and/or restore hope by facilitating hoping processes in some way. Some sources are internal to the person, some are external. They may be catalysts or initiators of the hoping processes or support processes already in motion.

THREATS TO HOPE

Equally important is to understand what threat-

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ens hope and hoping processes.

Threats to hope are the converse to the sources. They are persons, things or conditions that: a) interfered with, inhibited or weigh against the possibility of maintaining hope or attaining the hope object; and/or b) weaken or eliminate the sources of hope. Threats to hope diminish, jeopardize or endanger hope, or impeded hoping processes.

There are numerous spiritual factors that can be regarded as sources of hope, such as belief in God's love and prayer practices, but there are also some that can be seen as threats. Examples: doubts about God's care and forgiveness; fear of punishment; uncertainty regarding religious beliefs, particularly belief about the existence of God and about an afterlife; loss of former church support; and unanswered prayers.

Similarly, sources of and threats to hope can be found in the behavior of those closest to the patient. To illustrate, I'll focus on one group of significant others, physicians. Physicians were sources of hope in my study, for example, when they discussed modes of treatment of the disease and/or symptoms and conveyed positive expectations about outcomes. They helped shape the hope objects and reinforced the patient's sense of hope.

On the other hand, some physician behaviors acted as threats to patients' hope. In most instances, the threatened object of hope was that the physician would improve their condition and/or provide symptom relief. Patients interpreted physicians' actions and comments as threats to other hopes such as hope to cope well, to be treated as an intelligent, worthwhile and feeling person, and other hopes regarding illness and functioning.

Other threats included failure to convey that the physician was aware of or concerned about specific symptoms; minimizing or contradicting patient's report of troubling symptoms; and failure to fulfill a promise such as administering chemotherapy himself rather than delegating it. (With the growth of palliative care education for physicians, we trust these threats are being reduced significantly!)

HOPE PROCESSES

When we have the opportunity to be with patients over time, we have the advantage of being able to pay attention to the ever-developing and changing features of hope. We can see its progression and movement based upon multiple factors interacting with the hoping person.

For example, Mrs. P was a 76-year-old woman who lived independently for many years following

her husband's death. She had one daughter, who lived nearby. The daughter and family were important to Mrs. P's life. Twenty years ago, she had been diagnosed with breast cancer, and treated with surgery and radiation. She had regular check-ups, a good diet and exercised with the hope not to have a cancer recurrence.

She was admitted to the hospital for a submucous resection for what was thought to be chronic sinusitis resulting in fatigue and dyspnea. She hoped the physician would clear her sinus and restore her strength and breathing allowing her to return home living independently. Unfortunately, her sinus biopsy showed cancer, as did a subsequent bone marrow biopsy. Her hope for a negative biopsy was dashed, but the physician offered her an alternative hope that the cancer would respond to chemotherapy (her prognosis without successful chemo was living only another three months.) Once chemotherapy was started, her blood pressure dropped dramatically. When she described the crisis, she said she thought she was dying. She felt so ill and defeated that she began to hope and pray for death, to be released from her body. She thought about her life and was satisfied with all her blessings. After a few days of improvement, however, her hopes shifted.

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We see here how a changed reality can change one's hopes. Mrs. P's hope of going home alone was temporarily abandoned during the critical illness period, but the hope was revived with new reality considerations. As she progressed, she renewed her hopes to join her friends at the theater and to do other activities she had previously given up on. The hopes were encouraged by her daughter and health professionals. There were certain hopes that were more important to her than others, and where appropriate, she concentrated her energies on actions that helped attain the important hopes first. She died exactly one year after her initial discharge. During that year, she lived what she considered to be a happy, healthy, *hope-filled* and involved life despite her decline.

HEALTH PROFESSIONALS AS SOURCES OF HOPE

At this point, consider how the behavior of health professionals serves as a source of hope. Certain attributes and actions of health professionals positively influence hope and hoping processes. For example, some of the attributes of physicians described by patients in my study included open, honest, solicitous, knowledgeable, experienced, considerate, accommodating, supportive and comfortable to talk with. Patients described nurses as sources of hope with attributes that include helpful, pleasant, kind, gentle, sensitive, conscientious, caring, accommodating and skillful.

Actions of health professionals can aid hoping processes. Health professionals can explore and assess hope with patients and families by observing and asking questions directly and indirectly related to hope, listening for expressions of meaning and purpose. They can contribute to patients' definitions of reality; encourage and assist patients in establishing realistic hopes and determining alternative ways to achieve them. Health professionals can provide opportunities for patients to express the significance, as well as the uncertainty, associated with their hopes.

By conveying an empathetic understanding of patients' fears and doubts, health professionals can assist patients to cope with threats to hope. Conversations related to coping with past challenges can help patients identify and build on their inner resources such as courage, endurance, faith, self-worth, personal power and humor. Sometimes, it is difficult for patients to see progress toward realizing their hopes, and health professionals can point out positive changes they observe.

When an object of hope is attained, health professionals can share the patient's and family's joy, using the success as a springboard for new hopes and reinforcing hope in general. When an object of hope is abandoned, health professionals can strengthen the person's ability to mourn the loss, to identify what is possible, and eventually to identify new hopes. When the grief of abandoned hope is not resolved, and investing further in the hoping process seems impossible, health professionals can share their own beliefs regarding what is possible and what is not. We can carry the flickering candle of hope for them until they feel ready to carry it themselves.

Our role as care providers was beautifully conveyed by Dr. de Sales Turner. "It is imperative when we are working with those whose hope is fading, we identify horizons of hope that have been extinguished and those that have not. Once

it is known what remains, we must do everything we can to feed and nourish these horizons while the individual struggles to take control over the issue(s) diminishing their hope."³

FALSE HOPE/FALSE DESPAIR

Hoping processes sometimes lead to the stance of maintaining hope that others regard as a "false hope," a wish not grounded in reality. Central to any health care intervention is an understanding of hoping persons' perceptions of reality, the implications of the perceived reality on the hope, and the functions hope is serving.

It is also important to understand the perception of the "false-hope" labeler. Deciding whose perception of reality is closest to what might be objective reality is often a difficult task. A fine balance and compatibility exists between truth-telling and hope-giving if done well. Health professionals need to abandon the phrase "There is no hope." Truly, where there is life, there is hope! This is brought home quite poignantly in the title of Studs Turkel's book, *Hope Dies Last*.

The health professionals' view of reality may sometimes be much more constrictive, and their imaginative powers more limited, than the situation warrants. They may be unwilling to tolerate the uncertainty and ambiguity that are part of the clinical situation. False despair has been described as the provision of truth and reality without any hope.⁴

David Kessler, in his book *The Needs of the Dying*, tells the story of Sara, a patient who expressed statements similar to patients in my own experience. Sara, a 72-year-old retired professional with a supportive family, was diagnosed with advanced metastatic abdominal cancer. She underwent surgery to remove the largest tumor. She and her family accepted the fact it was only a matter of time before the smaller tumors became life threatening. Sara heard from a friend about an experimental treatment that might shrink the tumors. In discussing the possibility with her physician, he downplayed the possibilities and stated compassionately, "Sara, face it; there is no more hope." Kessler continues: "She paused, then seemed to inflate herself with strength that arose from somewhere deep down inside. 'My hope is mine. I've had it all my life. Sometimes it becomes reality; sometimes it's just hope. I plan to keep my hope. In fact, I plan to die with it. So we can evaluate this experimental treatment but not my hope.'"⁵ Like Sara, we all need to live with our hope and die with it.

Drawing from the above example of Mrs. P, a

nurse considered her hope to go home alone a false hope. After talking further with Mrs. P and learning about ways in which she had managed in the weeks prior to the hospitalization when she felt even weaker than in her present situation, the nurse changed her view. There is a tendency for health professionals to define reality in terms of medical probabilities when, in fact, many people mobilize unseen resources that allow them to far exceed medical probabilities. So whose reality is correct? It is important for patients and caregivers alike to keep multiple possibilities within view.

INFLUENCE OTHER SOURCES OF HOPE

Health professionals can also support hope in patients when they influence patients' perceptions about—and foster confidence in—other sources of hope, once they identify what those sources might be. For example, health professionals can convey honest confidence that the physicians, treatments, etc. can affect a positive outcome reinforcing the physicians and treatments as sources of hope for specific hopes. Since for many patients other people's similar experiences are a source of hope, caregivers can draw from the patient's observations of others. Caregivers should listen to and encourage patients' expressions of hope, concerns, reflections on meaning of suffering, their spirituality, life experiences, personal worth, and views on living and dying. All of these can be sources of hope, and if they start to become threats, the health professional might assist in the process of reframing them as sources of hope. Sometimes it is just in the telling that threats can be transformed to sources.

Health care professionals ought to support patients' loved ones. Loved ones can be great sources of hope, but need support, not only toward their involvement with the patient, but also for their own needs, especially when it comes to understanding what is happening. Helping patients identify role models from whom they may draw courage and strength is also something caregivers can do.

ACHIEVING SPECIFIC HOPES

Health professionals can and do assist patients and their loved ones achieve specific hopes. Following are just a few examples of areas where health professionals play a significant role:

- Symptom management, relief, and prevention
- Assist in meeting spiritual and religious needs; meaning and purpose

- Independence in functioning; “getting back to normal”
- Assistance with activities of daily living
- Strengthen ability to cope
- Promote and support relationships with significant others
- Treat with respect
- Assist with peaceful painless death, with loved ones near

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APPLICATION BEYOND PATIENTS

Everything so far relates to understanding hope of patients with life-threatening illness, but it has an important application to others as well. We can think about the hope and hoping processes of family caregivers. We can also think about hope and hoping processes of health professionals, not only related to patients and families we care for, but also in terms of health professionals' hope for themselves and their families. Think about your own hope and hoping process. What are the hope sources and threats in your own life and ministry as a care provider? It is worth paying attention to them. How do you keep the flame of hope burning?

I certainly had the opportunity to reflect on my own personal and professional hope and hope processes this past year as I dealt with my breast cancer diagnosis, surgery, chemotherapy and radiation; and with my mother's progressive dementia, dying process and death. I had many sources of hope throughout this challenging time, and reflecting on them has certainly benefitted me professionally and personally. Sharing our hope stories with one another is important as we continue to carry out this healing ministry.

TRANSFORMING SUFFERING

Consider these words of the Chilean poet Pablo Neruda. He knew personal pain and suffering and

knew how to extend compassion toward others in their suffering. I think this expresses what we are about as a community of palliative care providers and where hope fits in our ministry.

Give me for my life
all lives,
give me all the suffering
of the whole world,
I am going to turn it
into hope.⁶

Similarly, we can turn to the late Cardinal Joseph Bernardin who wrote the beautiful pastoral letter on health care titled "A Sign of Hope" while he was being treated for pancreatic cancer. Among the things he said, is this:

As Christians, we are called, indeed empowered, to comfort others in the midst of their suffering by giving them a reason to hope. We are called to help them experience God's enduring love for them. This is what makes Christian healthcare truly distinctive. We are to do for one another what Jesus did: comfort others by inspiring in them hope and confidence in life. As God's ongoing, creative activity in the world and the love of Christ make it possible for us to continue to live despite the chaos of illness, so too our work in the world must also give hope to those for whom we care. Our distinctive vocation in Christian healthcare is not so much to heal better or more efficiently than anyone else; it is to bring comfort to people by giving them an experience that will strengthen their confidence in life. The ultimate goal of our care is to give to those who are ill, through our care, a reason to hope. . . . Although illness brings chaos and undermines hope in life, we seek to comfort those who are ill, whether or not they can be physically cured. We do by being a sign of hope so that others might live and die in hope. It is the reason we are present to believers and nonbelievers alike.⁷

CONCLUSION

The words of Neruda and Cardinal Bernardin reinforce the Catholic health ministry's Shared Statement of Identity: "By our service, we strive to transform hurt into hope." Palliative and hospice care provide us with daily opportunities to witness hope at work amidst suffering. Through our vital ministry, we are able to fan the flames of hope in others and in ourselves as we continue answering the call to service. ■

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NOTES

1. Karin Dufault, *Hope of Elderly Persons with Cancer*, Doctoral Dissertation (1981) Case Western Reserve University.
2. Dufault, *Hope of Elderly Persons with Cancer*; and K. Dufault and B. Martocchio, "Hope: Its Spheres and Dimensions," *Nursing Clinics of North America* 20, no. 2 (1985): 379-391.
3. de Sales Turner, "Hope Seen through the Eyes of 10 Australian Young People," *Journal of Advanced Nursing* 52, no. 5 (2005): 517.
4. C. Nikolaichuk and E. Bruera, E., "On the Nature of Hope in Palliative Care," *Journal of Palliative Care* 14, no. 1 (1998): 36-42.
5. David Kessler, *The Needs of the Dying: A Guide for Bringing Hope, Comfort, and Love to Life's Final Chapter* (New York: Harper, 2007): 10-11.
6. Pablo Neruda, "The Invisible Man," *The Poetry of Pablo Neruda*, ed. Ilan Stavans (New York: Farrar, Straus and Giroux, 2005).
7. Cardinal Joseph Bernardin, "A Sign of Hope: Pastoral Letter on Healthcare," (Archdiocese of Chicago: October 18, 1995), 4-5, 7.

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