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ESSAY/PERSONAL REFLECTIONS

Hope at the end of life: Making a case for hospice

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The greatest dignity to be found in death is the dignity of the life that preceded it.
This is a form of hope we can all achieve, and it is the most abiding of all.
Hope resides in the meaning of what our lives have been.
S.B. Nuland, 1994, p. 242

INTRODUCTION

Hope is the anticipation of something better to come and an essential component of life. It is a complex notion that is fundamental to the promise of health care. Initially, hope is for cure or restoration of health but in terminal illness, when there is no longer the possibility of cure, hope rests in the knowledge and skill of the medical scientist to alter the course of disease and to prolong life. It is this expectation for renewed physical being that is the focus of every intervention. At the end of life, when science can do no more, hope endures, but the focus of hope changes. It becomes hope to find meaning in life, as it was lived, and in the time that remains. For most, however, the end of life unfolds in the scientific milieu of the hospital where the significance of redefining hope may not be considered, and many die without hope. The purpose of this article is to explore the meaning of hope, to highlight the necessity of redefining hope at the end of life, and to emphasize the importance of sanctuary in engendering hope through relationship. Hospice is proposed as a sanctuary for the final days, where the patient, family, and health professional discover a new meaning of hope through shared human experience.

THE MEANING OF HOPE

Hope is "the expectation of a good that is yet to be, a perception of a future condition in which a desired goal will be achieved" (Nuland, 1994, p. 223). Although the meaning of hope is unique to each, hope is common to all. For most, this includes being loved, having friends and family to love, and living a long and healthy life. It is within this expectation that hope dwells. The foundation of hope is "belief in a reality that transcends what is available as evidence" (MacIntyre, 1979, p. 7), a shift from the present reality to a new awareness of something greater and more lasting. The capacity of human beings to have hope is experienced throughout life; it is what drives us forward, keeps us going, and energizes us.

There is an element of reciprocity in hope, for when hope falters, it is renewed through the hope of another. In community with others, a sense of self-worth and a deeper understanding of hope emerge. Hope gives strength to overcome difficult situations, courage to go where one has never been before, and wisdom to find meaning in life and dying. This is particularly significant in circumstances that threaten life and consequently one's existence.

REDEFINING HOPE

In the final days, when medical science can no longer offer the promise of cure or prolongation of life, hope, of necessity, changes. There is still an expectation for a positive future. However, the focus of hope is different; it rests more in *being* than *doing*. When the probability of death is imminent and the need for finding meaning more acute, relationship becomes more important and more intense. It is in relationship, a profound experience shared by humans as they join together on the

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journey through life, that a new meaning of hope is found. Nouwen suggests that "the real question before our death, then, is not, How much can I still accomplish, . . . but, How can I live so that I can continue to be fruitful when I am no longer here among my family and friends? That question shifts our attention from doing to being." (Nouwen, 1994, p. 41) *Being* affirms that one is like the other "where it is safe to be oneself, to be unguarded," (Bolen, 1996, p. 122) ". . . for grace to enter, for love to be present, or for one soul to touch another" (Bolen, 1996, p. 125). Most simply, in *being*, "the common cry of humanity" (Roy, 1999, p. 4) is heard. Help me. Listen to me. Stay with me. Remember me. In the final days, this cry intensifies.

THE CHALLENGE

Redefining hope at the end of life is crucial; it can make the difference between going on or giving up. Yet, its redefinition presents a challenge. Why might this be? In the hospital, the scientific perspective prevails and this serves well through much of the experience of terminal illness. Science aids immensely in unraveling the complexities of advanced illness, by "doing" something to fulfill its promise to "make things better." However, believing that science is omnipotent can also lead to an expectation that it is the answer to everything. But what happens when science cannot fix everything, when it reaches its limit and nothing more can be done? Does this mean that hope no longer exists? Or does it mean that a new meaning of hope is needed? There is never a time when nothing more can be done. It is then that the meaning of hope shifts from the *doing* of science with its limitations to the possibilities inherent in *being* human.

What is it that happens to relationship, crucial to redefining hope, in a milieu dominated by science? On close examination, the mandate of science reflected in health care is to "fix a problem." To do this, the scientist is required to differentiate between self and other, the patient, between the one who seeks a solution and the one who is the problem. To study "the problem" objectively, science requires distance, detachment, and differentiation, whereas relationship requires sameness, closeness, and connection between two human beings. It is obvious that the requirements of science and relationship are incongruous and when science prevails, relationship is profoundly impacted (Hawthorne et al., 2002). This is evident in frequent references to the patient as "the dying" or "the terminally ill" and the health professional as "the expert."

The patient and the health professional are humans, not objects of study nor detached experts fixing problems. They are more the same than different and need connection not detachment, closeness not distance. When death is imminent, there is a deep need to join together in relationship to redefine hope and thereby reaffirm a purpose in life. Yet many spend their final days in the scientific milieu of the hospital, where *doing* is easier to envisage than *being* because it involves achievement and activity. We suggest that this may not be the best place because hope at the end of life reaches far beyond the boundaries of science. Hope in medical science to "make things better" is gone. However renewed hope emerges in the *being* of relationship. We propose sanctuary as the milieu of choice for the end of life, where the contribution of science is valued, but does not dominate, where *being* is as important as, and possibly more important, than *doing*.

MAKING A CASE FOR HOSPICE

Originally, the words *hospes* and *hospitium* were used to denote not only a certain relationship between individuals, but also the place in which the relationship developed. Later, *hospice*, derived from these words, described a place of refuge for weary or sick travelers seeking rest on life's journey. Today, hospice refers to a "program" of care for "the dying," a "type" of care synonymous with palliative care, or a "location" of care in the community, a reflection of scientific thinking regarding the end of life. We contend that it is imperative to return to the original meaning of hospice as a place of refuge, a sanctuary, where human relationship prevails and science is an invited guest.

Hospice as a place of refuge means a place of reflection and hope, where the journey through the final days is made not alone but with another, where the patient, family and health professional need each other and understand each other beyond words. They are touched by the warmth of human relationship to the depth of their souls, sharing the mystery of dying and death. It is here that hope is renewed through a sense of connection as part of the human family. At this immensely important time, there is "the possibility to experience a depth of relationship . . . that cannot be replicated in any other way" (Hawthorne et al., 2003, p. 265). The end of life is a time for forgiveness and wisdom, for thanksgiving and final reunion. It is here, in this place of sanctuary, that the possibility for a gentle closure to life awaits.

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CONCLUSION

Hope is essential to human life. In health care, hope revolves around altering the course of disease and prolonging life. However, when medical science can no longer offer hope, the patient, family, and health professional may experience a crisis of hope. At the end of life, a new meaning of hope is sought, one that is fostered through human relationship rather than through the miracle of science. The challenge lies in the fact that for most, the final days are spent in a place where science prevails and where the significance of redefining hope through relationship may not be acknowledged. Therefore, the end of life comes without the possibility of finding a new meaning of hope, hope in the fullness of *being* through human relationship.

Returning to the original meaning of hospice, where hope at the end of life is renewed in relationship, opens up new possibilities. It directs our attention to what is really important in life, to what human life is, in the end, all about. Most simply, as part of the human family, we uphold one another as we share the triumphs and tragedies of life. Reflection on dying and recognition of the importance of redefining hope at the end of life require a "profound wisdom and understanding, beyond knowledge, that touch and draw upon the human heart and soul" (Watson, 2003, p. 197). A deeper sensitivity and understanding of the meaning of hope at the end of life reminds us all of our shared humanity and the mystery of life and death. Providing the sanctuary of hospice at the end of life is a gift for all, the patient, the family, the health professional, and the human community.

> We are simply human beings, enfolded in weakness and in hope, called together to change our world one heart at a time. (Vanier, 1999, p. 163)

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