
The Meaning of Hope in Health and Illness

by Cheryl L. Nekolaichuk

Hope plays an important role in the illness experience, yet it is a difficult concept to articulate, given its complex intangible nature. To develop a model for capturing the personal meaning of hope in health and illness, I developed a questionnaire and distributed it to 550 healthy adults, adults with illness experience, and nurses. Major findings from this study suggest that people experience hope within three interconnected realms: personal spirit, risk, and authentic caring. This multidimensional framework provides a novel approach for understanding the complex experience of hope in health and illness.

Although hope is a commonly used word in every day life, its meaning eludes many people. When asked, *What does hope mean to you?*, some casually reply that they have never given much thought to the word. Others attempt to describe how the meaning of hope changes when they are confronted with challenging life events. Many have difficulty expressing their ideas abstractly and prefer to speak about hope from personal experience, for example, by recounting an image or a story that has special meaning (Jevne 1991, 1994). The nature of the experience shapes their responses to this puzzling question.

Among adults with illness, the same question elicits a diversity of responses. Some envision hope as "a life and healing force," raising it to an enviable position of ultimate power. Others see hope as "a false or unrealistic belief," quickly devaluing it to

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a position of futility. Still others speak of hope in terms of a "moment" or a "thread," as though to acknowledge its fragile and fleeting nature. Many describe the experience of hope as an inner struggle — a struggle between "being too hopeful" and "not being hopeful enough" — as they strive to master this fragile force.

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Despite its tenuous nature, the thread of hope is woven into the fabric of each person's illness experience. For some, the threads are tightly woven, while for others they are raveling strands. Many people living with chronic and life-threatening illness use the word "hope" to describe their illness experiences: "I hope to get better." "When I was told about my diagnosis, it took away all my hope." The thread of hope may be intricately interwoven with other experiences, such as compassion, caring, healing, trust, courage, meaning, faith, optimism, resiliency, uncertainty, and despair. A number of people have written about the link

between hope and other related concepts in an effort to better understand its complexity (e.g., see Farran et al. 1995; Fitzgerald 1979; Pruyser 1986).

Although each person's weaving is unique, hope itself transcends individual experience. This transcendent quality captures an important component of hope. For many, hope is a shared experience strengthened in relationships. The relational aspects of hope form an important part of a larger multidimensional experience (e.g., see Dufault and Martocchio 1985; Farran et al. 1995). Patients have identified "relationships" as an important hope-inspiring strategy (Herth 1990; Miller 1989). These relationships may be in a variety of forms, including relationships with people, nature, animals, and God or some other higher power. Thus, people who are isolated and alone may still experience "hope in relationship," as witnessed by the powerful stories of people who have survived traumatic life events, such as captivity and isolation in concentration camps (e.g., see Frankl 1962).

Within the illness context, most patients and practitioners would agree that hope plays an important role in the patient-caregiver relationship (Benzein and Saveman 1998; Herth 1990; Koopmeiners et al. 1997; and Perakyla 1991). Not everyone, however, views hope in the same way all the time. From my clinical work in a cancer facility, I vividly recall one patient's image of hope as "life in the desert." Despite its desolation and desiccation, the desert teems with life; and hope, like desert plant and animal life, flourishes amid the sparseness.

In sharp contrast, a professional caregiver found his image of hope embedded within a statistical framework. People who outlive their prognoses are the fortunate few who happen to fall in the upper end of a probability curve.

An elderly, terminally ill woman had yet another perspective. She experienced little quality in her life and wanted to die but felt that everyone was denying her this option by "forcing her to be hopeful." Only when given the freedom to choose did she embrace hope itself, shifting from a state of

despair to an affirmation of life. These contrasting views heightened my awareness of differences in the personal meanings and value of hope, and how these values may change over time.

In spite of evidence from the clinical setting, the personal meaning and value of hope is often lost in the literature. Diverse definitions and frameworks have been used in efforts to depict a model of hope (Dufault and Martocchio 1985; Farran et al. 1995; McGee 1984; Owen 1989; Snyder 1994; Stotland 1969). Most of the models, however, focus more on the common elements of hope than on its unique features. In addition, the use of abstract concepts and confusing terminology obscure the personal experience from which the models are derived. There is, then, no universally accepted model or definition of hope. This disparity between clinical experience and theoretical descriptions of hope in the literature prompted me to ask the following question: *How can we develop a model that will capture the uniqueness and dynamic nature of the human experience of hope?*

Beginning with the Personal

To answer the question, I developed a research tool in the form of a questionnaire (Nekolaichuk 1995) containing six concepts related to hope. Participants in the study were asked to share their personal views about hope by rating each hope-related concept, against a set of fifty adjective pairs. The first three general concepts were presented in the form of questions:

- (a) What does the word "hope" mean to you?
- (b) How would you describe a hopeful person?
- (c) How would you describe a person without hope?

The other more specific concepts were presented in story format. First, I presented a structured story about a person who maintained hope in spite of adversity, and, second, a structured story about a person who had lost hope. The third story was unstructured and gave participants an opportunity to describe their personal hope stories. A sample of the questionnaire format, using the third story, *A Personal Story of Hope*, appears in Figure 1.

A Personal Story of Hope¹

Think of a time in your life when your own hope was very much challenged. This may be a personal experience or it may be an experience of another individual. Briefly describe this experience in the space provided.

How would you describe your hope relative to this experience?²

- 3 - extremely
- 2 - quite
- 1 - slightly
- 0 - equally or neither

	3	2	1	0	1	2	3	
negative	___	: ___	: ___	: ___	: ___	: ___	: ___	positive
cold	___	: ___	: ___	: ___	: ___	: ___	: ___	warm
honest	___	: ___	: ___	: ___	: ___	: ___	: ___	dishonest
trusting	___	: ___	: ___	: ___	: ___	: ___	: ___	mistrusting
realistic	___	: ___	: ___	: ___	: ___	: ___	: ___	unrealistic
tender	___	: ___	: ___	: ___	: ___	: ___	: ___	tough
pessimistic	___	: ___	: ___	: ___	: ___	: ___	: ___	optimistic
confronting	___	: ___	: ___	: ___	: ___	: ___	: ___	withdrawing
accepting	___	: ___	: ___	: ___	: ___	: ___	: ___	rejecting
helpful	___	: ___	: ___	: ___	: ___	: ___	: ___	harmful
sad	___	: ___	: ___	: ___	: ___	: ___	: ___	happy
connected	___	: ___	: ___	: ___	: ___	: ___	: ___	disconnected

¹ Each hope-related concept was rated against 50 adjective pairs. For illustrative purposes, only a portion of the adjective pairs has been included.

² Participants were provided with detailed instructions for completing the questionnaire. For each adjective pair, they were asked to place a check-mark at the point that best described their hope, ranging from the extreme of one adjective to the extreme of the other.

Figure 1. — An example of a hope-related concept, *A Personal Story of Hope*, taken from the Hope Questionnaire (Nekolaichuk 1995)

This questionnaire was distributed to 550 people. Of this total, 146 had never had an illness; 159 had had a chronic or life-threatening illness at some point in their lives; and 206 were nurses or nurses-in-training. The remaining 39 respondents were not classified in these categories.

Identifying a Model of Hope Based on Personal Meaning

The major findings from this study suggest that people experience hope in three interconnected realms: *personal spirit* (personal realm), *risk* (situational realm), and *authentic caring* (interpersonal realm) (Nekolaichuk et al. 1999).

Respondents experienced hope primarily as an inner experience, which I have labeled the realm of *personal spirit*. This realm represents a holistic experience of hope, revolving around a core theme of meaning. The experience of hope within situations is the realm of *risk*. In this realm, the experience of hope is influenced by the predictability of a situation and a person's boldness. Predictability in some aspects of a person's life may enhance the individual's boldness or willingness to risk in other areas of life. The interpersonal realm of *authentic caring* represents the experience of hope within relationships. It is influenced not only by

comfort and caring, but also by credibility. Comfort and caring, alone, may not be sufficient for the experience of hope within relationships.

This model enhances our understanding of the hope experience in three unique ways. First, it offers a multidimensional perspective on hope that is grounded in personal experience. The holistic nature of the personal realm suggests that hope cannot be compartmentalized. Second, this model reinforces the need to balance predictability with uncertainty in different areas of a person's life. Third, it highlights the importance of credible, caring relationships as a part of the hope experience.

Exploring Hope in Practice

This multidimensional view of hope has important applications within the clinical setting. Using it as a template, a number of key questions can be generated to help clinicians explore the role of hope within helping relationships. Before they can help other people understand their experiences, however, it is equally important that clinicians understand their own experience of hope. Thus, questions can also be generated to help clinicians explore their personal experience of this complex concept. A summary of the model and key questions for reflection appear in Table 1.

To further illustrate the use of this framework in practice, I will present two cases. To protect the patients' identities, the cases have been modified sufficiently to represent a composite of experiences.

Peter's story

Peter is thirty-nine years old. He is married and has an eight-year-old son and six-year-old daughter. Peter has developed a successful line of work as an architect. He has always been a very athletic person, despite living with ulcerative colitis for the past ten years. Peter has always placed a lot of hope in the health care system and has been pleased with the care he has received for his colitis. Although he is satisfied with his work accomplishments, Peter's family is the most important part of his life.

At a time when he should be enjoying his successes, Peter is facing a new challenge. About

one year ago, Peter was diagnosed with liver cancer. Two operations have helped relieve some of his symptoms, but his health has steadily declined, to a point where he is no longer able to work. At his last medical appointment, Peter's surgeon told him, "You have a few good years left, and you should enjoy yourself."

Peter is feeling quite weak physically and somewhat uncertain about his future, though he still has a positive outlook. He decides to get a second opinion from another physician to see if he has any other treatment options. At this appointment, the doctor tells Peter to "go home and settle your affairs." He is quite concerned that Peter has not discussed the seriousness of his illness with his children and asks, "Have you told your eight-year-old son how sick you are?" Peter is devastated by this news. He loses all hope and sinks into a deep depression. He becomes isolated from his family and friends, and sees no hope to keep on living.

Angela's Story

Angela, a fifty-five-year-old woman who has breast cancer that has spread to her bones, is in the hospital for management of her symptoms. When she was first diagnosed, Angela was told that she had "less than a year to live." At that time, she decided to make the most of her life. "Instead of sitting in front of the TV and eating 'bon-bons,' I decided to go to nursing school," Angela remarked.

Fifteen years later, Angela no longer has dying on her agenda. Even though she has been told that the cancer has spread, she continues to live each day gratefully. When asked what has kept her going over the past fifteen years, Angela says, "There was a spirit inside of me that nobody could flatten . . . and nothing has. I've always been a very hopeful person."

Angela speaks about the uncertainty of her condition, knowing that someday she will be "going to a better place," yet not knowing when that time may come or who will be by her side in the final hours of her life. For Angela, time passes "thoroughly." She remarked, "I watch [time] go [by] at the same speed for you, only you run around

Table 1. — A Clinical Model for Understanding the Personal Experience of Hope

Hope Framework	Questions for Reflection		
	Questions for the Helping Relationship	Questions for the Patient/Client	Questions for the Clinician
<i>Personal Spirit</i> (meaning)	<p>If we encourage people to search for meaning in their lives, then what influence will it have on their experience of hope?</p> <p>How might our relationships contribute to what is meaningful in other people's lives?</p>	<p>What is meaningful in this person's life?</p> <p>How does this person make sense of her/his world?</p> <p>What would need to happen to enhance the meaning in this person's life?</p>	<p>What is meaningful in my life?</p> <p>How do I make sense of the world?</p> <p>What would need to happen to enhance the meaning in my life?</p>
<i>Risk</i> (predictability and uncertainty)	<p>How can we create a sense of safety in our relationships that will encourage people to take risks?</p> <p>How do we encourage people to consider new possibilities without overwhelming them?</p>	<p>What is this person's willingness to risk?</p> <p>What is this person's tolerance for uncertainty?</p> <p>What are the predictable elements in this person's life?</p>	<p>How am I handling the uncertainty in my life?</p> <p>How have I handled times of uncertainty in the past?</p> <p>What are the predictable elements in my life?</p>
<i>Authentic Caring</i> (comfort and credibility)	<p>How might my credibility influence other people's experiences of hope?</p> <p>How do we develop and maintain caring and credible relationships?</p>	<p>Who authentically cares about this person?</p> <p>About whom does this person care?</p>	<p>Who authentically cares about me?</p> <p>About whom do I care?</p>

Adapted from C. L. Nekolaichuk (1995). *An exploration of the meaning of hope in health and illness*. Unpublished doctoral dissertation, University of Alberta, Edmonton, Alberta, Canada.

like a mouse in a cage. I spend each moment consciously . . . [consciously] aware of each moment."

Angela is divorced and has no children. However, she identifies a number of important relationships in her life that give her hope: five-year-old Mark who lives in the inner city, her mother who is no longer alive, the nurses caring for her in the hospital, and her belief in the "Great Spirit." Despite these supports, she acknowledges

the limited time that people have to spend with her and her fear of dying alone.

"I think," she says, "the biggest pain to go through in the end . . . is the gradual dropping away of visitors. I hope my friends keep their promises. Promises about sitting with me and being with me when that time comes." The importance of relationships as a part of the hope experience rings through Angela's words: "There's no hope for man unless we start touching each other with love. You

know, there's no touch. You can spend days and days without being touched."

Case Syntheses

The reality of a life-threatening illness confronts us with our mortality — whether we are the person diagnosed with the illness, a family member, or a professional caregiver. Peter and Angela are confronted by life's finitude and both must struggle to maintain hope in the face of adversity. Their cases illustrate two very different experiences of hope within the context of a life-threatening illness. Peter has spiraled down to the depths of despair, while Angela has been able to rise above adversity, maintaining some sense of hope in spite of the odds. How can we explain the differences?

"There's no hope for man unless we start touching each other with love. You know, there's no touch. You can spend days and days without being touched."

Peter's experience of hope revolves primarily around his relationships — his family and his professional caregivers. In terms of hope, Peter's emphasis is on the realm of authentic caring. Although at some level he is aware of the uncertainty of his illness, he continues to hope for, and to seek, some form of treatment. When his physician offers him a message of "no hope," Peter is devastated.

How would you go about helping Peter regain hope in his life? How would you try to "repair" the hope that has been inadvertently damaged by his physician's words? It may be helpful to explore Peter's experience of hope, using the three dimensions of personal spirit, risk, and authentic caring. The following questions can be used as part of this exploration: What can give Peter some meaning in his life at a time when everything seems so hopeless?

Although hope for a cure may no longer be an

option, what other hopes might Peter consider? hope to spend quality time with his family? hope for comfort and pain relief? hope for a peaceful ending to his life? How can Peter begin to reestablish connections with people who care about him and are willing to support him through this difficult time in his life?

Angela was also given "bad news" about her cancer diagnosis, yet followed a very different path. She had a strong sense of personal spirit that she had developed throughout her life. Rather than giving up, she brought new meaning to her life by enrolling in nursing school, never thinking that she would live to provide care to others. She was willing to take risks, in spite of the uncertainty of the illness.

The presence of credible, caring relationships was also an important component of Angela's hope experience. Even though she spent a great deal of her time alone, her ability to bring these relationships to life in different ways sustained her through the darker moments. Despite her sense of spirit, willingness to risk, and the presence of authentic caring relationships, she did not deny the reality of her illness or her fears about the possibility of dying alone.

What have we learned?

Although hope is a universal experience, it is also an intensely personal one. No two people will experience hope in the same way when faced with adversities, such as a life-threatening illness. Each experience will be unique and will integrate many dimensions of a person's life. The three components of hope described in this article — personal spirit, risk, and authentic caring — provide a framework for understanding this highly individualized experience.

This study helps enhance our understanding of the meaning of hope in health and illness, from both a theoretical and clinical perspective. Theoretically, it contributes to the future development of models that emphasize hope as a dynamic and unique experience. Clinically, or within the context of illness, it enhances our understanding of an individual's personal sense

of hope and contributes to a more effective patient-caregiver relationship. Personally meaningful strategies can be developed that will enhance hope for both patients and health care professionals. The model in this study may also allow us to chart a person's perspective of hope over time, thereby capturing the dynamic nature of this experience.

We learn most about the personal meaning of hope from our clinical experiences and relationships. When, however, we try to share our insights through the literature, the personal meaning of hope is often lost in a myriad of abstract theoretical descriptions. This gap between clinical and theoretical expressions of hope creates an artificial dichotomy. This study bridges the two realms by integrating the personal experience of hope within the theoretical mapping of a hope model. It has the potential to contribute, both clinically and theoretically, to the development of this complex, elusive concept.

This study has sparked new thought and opened new doorways into the exploration of hope. Its findings suggest that the experience of hope is a holistic, interconnection of personal spirit, risk, and authentic caring grounded in a core theme of meaning. Many questions have emerged from these findings that can provide a framework for further study. My hope is that this study will serve as a catalyst for further exploration, as we continue to search for the elusive answer to the question, *What does hope mean to you?*

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