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**PURPOSE.** To discuss the concept of hope, factors influencing hope, assessment, and hope-fostering strategies as described in the hospice/palliative care scientific literature.

**DATA SOURCES.** Published research studies focusing on hospice patients.

expectation for a positive future, an inner resource, and a process that helps patients endure suffering. It is influenced by physical condition, pain, faith, and caring relationships. Eight suggested hope-fostering strategies are proposed. Conclusions. Nonterminally ill and terminally ill patients view hope differently. Assessment of hope and hope-fostering strategies should be incorporated into the interdisciplinary plan of care. Implications for nursing practice. The assessment of hope and hope-fostering interventions will assist hospice patients in dealing with their terminal illnesses and increase their quality of life.

**Search terms:** Hope, hope-fostering strategies, hospice care, palliative care

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## Hope Is a Thing With Feathers

Hope is the thing with feathers
That perches in the soul
And sings the tune without the words
And never stops at all
And sweetest in the Gale is heard
And sore must be the storm
That could abash the little Bird
That kept so many warm
I've heard it in the chilliest land
And on the strangest sea
Yet, never in Extremity,
It asked a crumb of me.

—Emily Dickinson, 1924.

**E**mily Dickinson's poem reminds us that hope provides comfort even during the worst of life's storms. Hope is so important that it has been described as being essential for existence (Stephenson, 1991).

The importance of hope in coping has been supported in research studies of patients with such chronic illnesses as cancer (Herth, 1989; Korner, 1970; McGill & Paul, 1993; Post-White et al., 1996; Weiseman, 1979), heart disease (Morgan, 1971; O'Malley & Menke, 1988; Rideout & Montemuro, 1986), and renal failure (Baldree, Murphy, & Power, 1982). It has also been found in several research studies to be associated with effective coping in the face of such uncomfortable side effects as pain (Cameron, 1993; Carson & Mitchell, 1998; Howell, 1994), continuing with daily activities, maintaining a functional role within the family (Post-White et al.), better quality of life (Herth), and spiritual healing (Cousins, 1989). Hope has been found to give meaning to the lives of well elderly people (Gaskins, 1995) and is associated with positive mood states in elderly people with cancer (Fehring, Miller, & Shaw, 1997).

In research studies of hospice patients, hope has also been found to be associated with positive outcomes. These studies suggest that hope facilitates coping with terminal illness (Bove, 1996; Hall, 1990; Herth, 1990; Perakyla, 1991). One study of the pain experience in elderly hospice patients suggests that maintaining hope is an important process in coping with pain (Duggleby, 2000a). Hope, therefore, is important for comfort and quality of life for hospice patients. The purpose of this article is to discuss the concept of hope, factors influencing hope, assessment of hope, and hope-fostering strategies as described in the hospice/palliative care scientific literature.

## Conceptualization of Hope

Hope is a complex concept that is often misunderstood, as people define hope differently. Healthcare professionals who define hope as being related to cure or remission of disease often view the hope of terminally ill patients as a form of denial or false reality (Hall, 1990). The outcome of this view is a decrease in the quality of life for hospice patients (Hall). Therefore, it is important for nurses to understand how hospice patients view hope so their own views and actions do not result in hindering the hope of hospice patients. Hospice patients have conceptualized hope as an expectation for a positive future (Hall), as an inner resource (Herth, 1990), and as a process for enduring suffering (Duggleby, 2000a).

#### **Expectation for a Positive Future**

Hope has been described as an expectation for a positive future or outcome (Yates, 1993). When the future is limited by terminal illness and the outcome is death, how can hope be viewed as positive? After interviewing 11 men with AIDS, Hall (1990) suggested that patients with a terminal illness view hope as a positive future by redefining their future. They view their future as one day at a time and focus their hope on living day to day. Hope, therefore, has a different focus for the terminally ill. Table 1 lists the different foci of hope, comparing the results of research studies of non-terminally ill and terminally ill participants.

Another example of the differences between the foci of hope for the non-terminally ill and terminally ill is that medical/surgical patients report focusing their hopes on "getting better," while palliative patients describe their hope for "feeling better" (Perakyla, 1991). Each group defined hope as an expectation of a positive future; however, palliative patients restricted that positive expectation to "feeling better."

The participants in a qualitative study of the pain experience of elderly hospice patients with cancer (Duggleby, 2000a) described their hope as hope for "relief of pain" and "not suffering anymore." Their focus of hope differed from non-terminally ill patients with chronic pain. In studies of chronic pain patients, participants reported that their hopes were related to getting better and living longer (Cameron, 1993; Carson & Mitchell, 1998; Howell, 1994).

Table 1. Comparison of Foci of Hope by Non-Terminally III and Terminally III Patients

## **Non-Terminally III Patients**

- Cure of disease or remission of disease (Post-White, 1994)
- Getting better (Perakyla, 1991)
- Relief of pain (Carson & Mitchell, 1998)
- Living longer (Cameron, 1993; Carson & Mitchell, 1998; Howell, 1994)
- Surviving (Post-White, 1994)

## **Terminally Ill Patients**

- Living day to day (Hall, 1990)
- Feeling better (Perakyla, 1991)
- Relief of pain (Duggleby, 2000a)
- Not suffering more (Duggleby, 2000a)
- Peaceful death (Bove, 1996; Greisinger et al., 1997)
- Life after death (Bove, 1996; Duggleby, 2000a)
- Hope for families (Greisinger et al., 1997)

Like the terminally ill, however, chronic pain patients also described hope for pain relief (Carson & Mitchell).

Hope for a peaceful death without pain was described by palliative care patients (Greisinger, Lorimor, Aday, Winn, & Baile, 1997). One of the participants said: "My hope is not for extra life; it's for a peaceful death. I also hope those close to me accept my death" (p. 149). The participants' hopes also included hope that their families would not suffer when they were gone.

Reuniting with their families after death was seen as a positive outcome for hospice patients who related their hopes to their spiritual beliefs. They described their hopes for "life after death," where they would have peace and comfort and be reunited with loved ones (Bove, 1996; Duggleby, 2000a). Life after death was viewed as a positive future, which gave the participants something to look forward to.

## **Inner Resource**

Based on the results of a qualitative study of 30 terminally ill hospice patients, Herth (1990) defined hope as "an inner power that facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being" (p. 1256). This inner power or resource helped participants to redefine their values and focus on themselves as a person rather than on what they could do or did do. This is different from definitions of nonterminally ill patients, as the focus of the hope shifts to being rather than having or doing (Herth).

#### **Process of Enduring**

Hope was described by participants in a qualitative study of the pain experience of elderly hospice patients with cancer as a process to endure suffering (Duggleby, 2000a). One participant described how hope helped her overcome her suffering: "Well, if you have hope . . . assurance of everlasting life . . . that in itself gives you an easier peace. You know you can overcome suffering" (p. 828). Trusting in a higher being and making meaning of their lives were described as ways the patients maintained

their hopes. Trusting in a higher being was based on their faith. Trust was more than faith, however. It was a reliance on a higher power to take care of them and ensure a positive future, whether that was a peaceful death or life after death. Making meaning of their lives gave the hospice patients a sense of self-worth, strength, and hope that they would be able to cope with their suffering.

Trusting in a higher being and making meaning of their lives were described as ways the patients maintained their hopes.

Maintaining hope has also been found to be a central theme in enduring in a study of trauma victims (Morse & O'Brien, 1995). Trusting in a higher being and finding meaning were not described as ways that non-terminally ill patients maintain their hope, however. Therefore, although there are similarities in the definition of hope, the ways terminally ill patients maintain hope may be different.

#### **Factors Influencing Hope**

Several factors influence hope: physical condition, uncontrollable pain and discomfort, caring relationships, and faith. Hope in hospice patients has been found to change over time related to the changes in their physical condition with the progression of the terminal disease (Bove, 1996; Herth, 1990). As the hospice patients' physical/medical conditions worsened, their hope no longer focused on time but rather on their families, close friends, and the meaning attached to life events (Herth). When death became imminent, a final change occurred: Hope was focused on the desire for serenity, inner peace, and eternal rest. Therefore, changes in the patient's physical condition have a significant influence on hope—not the quantity of hope but rather the focus of hope.

Terminally ill patients have also reported that pain and discomfort *negatively* influence their hopes (Herth, 1990). It was not, the presence of pain, however, but rather the continuation of uncontrollable pain that had an impact. The outcome of uncontrollable pain was overwhelming fatigue and lack of energy to invest in the hoping process.

Faith and caring relationships were also identified as factors that influence hope in elderly hospice patients with cancer (Duggleby, 2000a). Faith was the foundation for trusting in a higher being who would take away their pain and not let them suffer: "I believe that God is kind and will not let his children suffer" (p. 828). Faith was also the foundation for the belief in life after death. As well, elderly hospice patients reported that caring relationships made them feel valued and gave them encouragement and hope that they would feel better.

Factors influencing hope for nonterminal chronic and cancer patients have also included physical condition (McGill & Paul, 1993), faith, and family and friends (Fehring et al., 1997; Post-White et al., 1996; Raleigh, 1991). A positive significant relationship was found between hope and functional status in a study of 88 community-living elderly with cancer (McGill & Paul). In a study of cancer patients (Post-White et al.), more than two thirds of the participants indicated their family members were sources of hope. They also reported spiritual strength, religion, and belief in life after death as sources of hope. Patients with chronic illness and cancer found family, friends, and religious beliefs had a positive influence on their hopes (Raleigh). Intrinsic religiosity and spiritual well-being had a significant positive relationship to hope in a study of 100 elderly patients with cancer (Fehring et al.). Therefore, the factors influencing hope in terminally ill patients appear to be the same as with the non-terminally ill.

## Assessment of Hope

An important aspect of fostering hope in hospice patients is the clinical assessment of hope, which is not typically part of routine practice. Based on the scientific liter-

ature, assessment of hope should be completed on admission, when major changes in physical status occur, and again when death is imminent (Herth, 1990). This assessment should also include other factors influencing hope, such as pain, faith, and relationships.

Several self-report instruments have been developed to measure hope (Farran, Salloway, & Clark, 1990; Herth, 1989, 1992; Miller & Powers, 1988; Stoner & Keampfer, 1985). Only one, however, has been evaluated and found to be reliable and valid in hospice patients. The Herth Hope Index (HHI) is a 12-item, 4-point Likert scale that delineates three dimensions of hope: temporality and future, positive readiness and expectancy, and interconnectedness (Herth). Included within these three dimensions are the concepts of faith and relationships. Because it is short, simple, easy to use, and has been positively evaluated in hospice patients, the HHI maybe a useful tool to assess hope in hospice patients. If the HHI were used in conjunction with a measurement of pain, the assessment of hope would be inclusive of the factors found to influence hope.

## Strategies to Foster Hope

Table 2 lists suggested hope-fostering strategies that the hospice team can use. These were developed from factors influencing hope, a research study identifying hope-fostering strategies described by hospice patients (Herth, 1990), and two studies describing hope-fostering strategies used by hospice nurses (Cutcliff, 1995; Herth, 1995).

#### **Facilitating Caring Relationships**

Caring relationships were identified by elderly hospice patients as being important to the maintenance of hope (Duggleby, 2000a). In caring and meaningful relationships, there was a willingness in participants to share a part of themselves with one another and to listen attentively to one another (Herth, 1990). Caring relationships were described by hospice patients as family, friends, and healthcare professionals who provided physical

### Table 2. Hope-Fostering Strategies

- Facilitate caring relationships\*
- Humor and play
- Encourage determination and courage\*
- Patients and family to set short-term attainable goals
- Facilitate the environment and resources for spirituality\*
- Reminiscing
- Physically present in crisis\*
- Listening attentively\*
- Pain management\*

\*Hope-fostering strategies reported as being used by hospice nurses (Cutcliff, 1995; Herth, 1995).

Note: Based on information from Cutcliff, 1995; Herth, 1990, 1995.

care, prayed with the participants, and smiled (Duggleby). Potential interventions in this category would be education of family and friends about the importance of maintaining caring relationships with the patients, provision of resources to facilitate caring relationships such as family counseling, and providing social support. Members of the hospice team, such as social workers, are skilled at assessing and facilitating social support. For those patients without established social support networks, hospice volunteers are invaluable in their willingness to listen attentively and provide encouragement to the patients and their families.

## **Humor and Play**

Lightheartedness formed a communication bond with others and a coping mechanism for hospice patients (Herth, 1990). Hospice patients participating in Herth's study defined lightheartedness as "feelings of delight, joy, or playfulness that is [sic] communicated verbally and nonverbally" (p. 1254). Humor and laughter were identified as sources of lightheartedness.

Hospice nurses can easily use the strategies of play and humor to achieve the lightheartedness described by the hospice patients. Humor has been found to have a positive influence on coping with painful illnesses (Ditlow, 1993). Simple interventions for humor may include comedy audiotapes and videotapes of the patient's favorite comedian, professional clowns, and pet therapy (Osterlund & Beirne, 2000).

#### **Encourage Determination and Courage**

Personal attributes of determination, courage, and serenity were described by hospice patients as making a difference in maintaining hope (Herth, 1990). Nurses can support and encourage these personal attributes. Methods of encouragement may include verbally recognizing the patient's positive attributes, positive feedback to the patient, and external rewards. An example of encouragement used by hospice nurses is the story of a hospice patient who was very determined to sit in his chair for his grandson's visit. The nurses let the family know how important this was to him and worked with the patient through exercise and energy management to support his wish. When the grandson came for a visit he brought a special button he had made his grandfather that said, "I am so proud of you, Grandpa." Pictures were taken of the grandson and the hospice patient who was sitting in a chair and were put in frames around the bedside following the visit.

#### **Setting Short-Term Attainable Goals**

Hospice patients report that aiming for and achieving something fosters their hope (Herth, 1990). Nurses can thus encourage patients and families to develop short-term goals or aims that are attainable. For example, completion of creative arts projects has been found to foster hope (Kennett, 2000). Many hospice patients have planned special trips or special family events, or have strived to finish reading a particular book. The aims must be related to something that has meaning for the patient, and the hospice nurse should elicit support from the patient's family and friends to achieve these aims.

#### Spirituality

The presence of active spiritual beliefs and practices fosters hope (Herth, 1990). Terminally ill patients have

described spirituality as a bridge between hopelessness and meaningfulness in life (Fryback & Reinert, 1999). The importance of spirituality has long been recognized in hospice programs, and a spiritual assessment and plan of care are required for all hospice patients. Hospice nurses are already involved in facilitating an environment and resources for hospice patients to express their spirituality and religious practices, thus fostering hope.

### Reminiscing

Activities that foster hope in hospice patients include sharing happy stories from the past and reminiscing through old picture albums (Herth, 1990). In the gerontological literature, reminiscing, life review, and oral histories are strategies that have been found to assist individuals to deal with unresolved conflicts, address past losses, find meaning in past events, and provide the individual with a sense of self-worth (Burnside, Rodriguez, & Trevino, 1989; Kovach, 1991). Therefore, the hospice team may use simple techniques such as journals, photo albums, and oral histories as strategies to foster hope.

#### **Physical Presence and Listening Attentively**

Hospice patients speak of "affirmation of worth: acceptance, acknowledgement, and honoring of one's individuality by others" (Herth, 1990, p. 1254) as important in fostering hope. Participants in Herth's study gave examples of volunteers, family, and friends who valued them as worthwhile human beings. Being physically present in times of crisis and listening attentively were important strategies for nurses trying to convey a sense of value. Abandonment and isolation conveyed to the participants that they were a person of little value and were therefore hindrances to hope (Herth).

## Pain Management

Anther hope-hindering factor was uncontrollable pain and discomfort (Herth, 1990). The issue of pain

management is a central theme in hospice and palliative care (Rankin & Mitchell, 2000). The nature of pain in hospice patients is physical, psychological, spiritual, and social, and therefore requires the expertise of the multidisciplinary hospice team to achieve pain relief (Duggleby, 2000b). Poorly managed pain in hospice patients interferes with comfort, ambulation, activities of daily living (Morgan, Lindley, & Berry, 1994), relationships with others, and hope (Duggleby, 2000a). Hospice patients reported that strategies for decreasing pain fostered hope (Duggleby, 2000a). The strategies, which were pharmacological and nonpharmacological, gave participants hope that their pain would be relieved.

## **Implications for Hospice Nurses**

Hospice nurses have identified hope as being highly important to those they care for (Herth, 1995). Although there is a need for more research on hope and hope-fostering strategies in hospice patients, published studies provide an understanding of how hospice patients conceptualize hope, factors that influence hope, and potential strategies hospice nurses can use.

The research supports the multidisciplinary approach used in hospice programs for assessment and interventions regarding social support, spirituality, and provision of comfort. Typical assessment does not incorporate an assessment of hope, however, and hospice nurses have reported in research studies that strategies they use to foster hope (Cutcliff, 1995; Herth, 1995) do not include the use of humor and play, setting short-term attainable goals, or reminiscing. The entire hospice team could also implement these additional interventions and include hope as a target for assessment and for intervention, in order to assist hospice patients in dealing with their terminal illness and increase their quality of life.

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# Legislative Update

On December 21, former President Clinton signed House Resolution (H.R.) 4577, which included the Medicare, Medicaid, and SCHIP Benefits Improvements and Protection Act of 2000 (BIPA, Public Law 106-554). The passage of this measure was an important gain in the coverage of hospice care under the Medicare program. BIPA included a 5% increase in the base payment for hospice care in fiscal year 2001, effective April 1, 2001. This measure was legislated by Congress to provide relief from the Balanced Budget Act of 1997 (BBA) and adjusted home health payments for fiscal year 2001 to the full market basket update. BBA 1997 reduced the Medicare hospice market basket update by 1% for fiscal year 1999 through 2002. Funding of home-hospice programs is especially important considering that the majority of Americans say they want to die at home versus the nearly 75% of terminally ill patients who die in hospitals and nursing homes. The Medicare hospice benefit began in 1983, and to date this coverage has been provided to more than 4.5 million beneficiaries.

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Search terms: Legislation, pain management

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