

CASE REPORTS

Exploring the therapeutic value of hope in palliative nursing

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ABSTRACT

Hope is a multi-dimensional concept that is integral to a dying person's needs. It is an essential resource that assists individuals with a life-threatening illness to cope during times of intense physical and psychological distress. The objective of this article is to explore and analyze the therapeutic value of hope. The phenomenon of hope will be explored through the analysis and application of Dufault and Martocchio's Multidimensional Model of Hope (MMH) to a clinical scenario. Factors determining hope in cancer patients as well as interventions that can foster hope in dying patients will be identified. Discussion includes examination of literature gaps, relevance to nursing practice, and practical strategies to engender hope and thereby enhance quality of life (QOL) in advanced cancer patients.

KEYWORDS: Hope, Factors affecting hope, Multi-Dimensional Model of Hope, Nursing, Palliative care, Cancer

CLINICAL SCENARIO

Mr. A, a 45-year-old man, living in France, was diagnosed as having a peritoneal carcinoma and partial bowel obstruction. He was informed by his doctor that his treatment options included symptomatic and palliative management rather than a curative treatment. Mr. A decided to come to Canada to seek a second opinion whereby he met various health practitioners including a homeopath. He started receiving Vitamin C infusion three times a week as an alternative treatment. He also visited the Oncology and Palliative Team at Joseph Brant Memorial Hospital (JBMH) where he was informed of various treatment options including chemotherapy and radiation. Mr. A was told that none of these treatments will increase his life significantly. Mr. A received chemotherapy; however, it made him increasingly weak. He was unable to eat and walk or even take a shower.

Finally, accepting the fact that none of the treatments would cure him, Mr. A reprioritized his needs and decided to opt for symptom management. He had severe abdominal pain that radiated to his lower back (scored 10/10) and had frequent episodes of vomiting (~6–7 times a day). Mr. A wanted his pain and nausea to be managed. He was prescribed several medications that alleviated most of his symptoms. Within three weeks, he had decided to visit his birthplace in England and also intended to go to Jamaica with his common law partner. Although Mr. A appeared very cachectic, he was always hopeful. He left for England on March 31, 2009. The authors remember that he said, "I am not giving up that easy," and feel that Mr. A's fighting spirit and hope maintained his quality of life (QOL).

Patients diagnosed with cancer may find the period between diagnosis and treatment to be the most stressful time, possibly because of the uncertainty and ambiguity about the disease and its prognosis (Balneaves & Long, 1999). Many early cases of cancer are cured because of the significant progress made by the medical field; however, many health

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professionals may find it challenging to address patient's needs when no further treatment options remain. We found Mr. A's situation particularly striking and we wished to explore the reasons behind his decisions to leave his country; to consider various treatment options; and to travel in his last days of life.

LITERATURE REVIEW

A comprehensive literature review was conducted using the electronic databases of OVID, MEDLINE, PubMed, CINAHL, and PsychINFO. Keywords used when searching the databases were "hope," "stress and coping," and "dignity." These terms were linked with "palliative care," "palliative nursing," and "oncology." The time frame for the literature search was set from 1990 to 2009, except for the article by Dufault and Martocchio that was published in 1985. The articles included a blend of qualitative, quantitative, and mixed methodologies. These studies focused on the meaning and perception of hope from the palliative patient's perspective; identified the factors affecting hope in terminally-ill patients; and recommended strategies to foster hope in cancer patients.

SIGNIFICANCE OF HOPE IN PALLIATIVE NURSING

Several researchers have attempted to explore the significance of hope in cancer patients. Hope is considered as one of the five major needs of a dying patient (Young-Brockopp as cited in Lin Chi, 2007, p. 416) and is viewed as a desire that an individual anticipates for the future (Clarke & Kissane, 2002). Dufault and Martocchio have defined hope as "a multi-dimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (1985, p. 380). Hope reflects an individual's perception about his or her ability to plan goals, develop strategies to reach the goals, and sustain the motivation to use the strategies (Synder et al., 2003). Hope serves as an anesthetic or insulation in the midst of hardship (Dufault & Martocchio, 1985) and can change a detrimental situation (Van Dongen, 1998). Hope is also viewed as an underlying concept in both "dignity" and "stress and coping" in terminally ill patients.

Hope is viewed as an important coping strategy that enables an individual to adapt to a difficult situation and allows personal adjustments during suffering (Ebright & Lyon, 2002). Felder (2004) performed a descriptive correlational study to explore hope and coping in 183 patients with gastrointestinal or geni-

tourinary, head and neck, breast, or hematologic malignancies. Hope was measured using the 30-item Herth Hope Scale whereas coping was assessed using the Jalowiec Coping Scale. A positive relationship was found between hope and coping style use ($p = 0.013$) and coping effectiveness ($p < 0.001$) indicating that patients with increased levels of hope can cope more effectively with their advanced stage of disease.

Hope is not only viewed as one of the coping strategies but is also associated with dignity in dying patients. Benzein et al. (2001) explored the meaning of the lived experience of hope in 11 cancer patients and revealed that hope enabled these patients to have a meaningful life and a dignified death. This finding can be further complemented through a study that was conducted by Chochinov et al. (2002). The researchers used a cross-sectional design to explore the association among various factors, including hopefulness and dignity in terminally-ill patients. The results of this study indicated a significant association between fractured dignity and hopelessness ($r = 0.46$, $p < 0.01$). This finding supports the notion that patients with increased levels of hope were able to maintain or enhance their sense of dignity regardless of the progression of their disease.

Hope is also linked with QOL in a dying patient. Herth (2000) utilized a quasi-experimental study to determine the influence of hope (as an intervention) on the QOL of 115 patients with recurrent cancer. The results of this study indicated that patients with higher levels of hope had enhanced QOL and thus hope was viewed as an important coping strategy to enhance the QOL in dying patients. Considering the therapeutic value of hope in cancer patients, one may ask: "what factors determine the level of hope in patients? Is the inspiration of hope in cancer patients a duty of the health professionals?" and "will it be considered remiss of health professionals to be ignorant of such a duty?" To answer many questions like these, the researchers have critically examined the concept of hope in the palliative setting.

CONCEPTUAL FRAMEWORK OF HOPE

Dufault and Martocchio (1985) explored the meaning of "hope" in 35 elderly cancer patients (≥ 65 years of age) and 47 terminally ill patients (≥ 14 years of age) over a period of 2 years. Based upon the themes that emerged from these two studies, Dufault and Martocchio generated a Multidimensional Model of Hope (MMH). This model incorporates particularized hope and generalized hope as its two spheres. It also focuses on the six dimensions that are involved in the process of hoping including the affective, cognitive, affiliative, behavioral, contextual, and temporal

dimensions. The two spheres along with the six shared dimensions influence one another and affect how the hoping process manifests itself.

The sphere of “generalized hope” refers to an overall sense of optimism that each individual possesses while accomplishing life’s daily tasks. It is a belief that one’s life holds some “future beneficial but indeterminate development” (Dufault & Martocchio, 1985, p. 380). Generalized hope is broad in scope and is not linked with any particular object of hope. It is described as an “intangible umbrella” that protects the hopeful individual like a shield and motivates to carry on with roles and responsibilities. Unlike generalized hope, the particularized hope is concerned specifically with desired outcomes or a state of being. Particularized hope enables a hoping person to clarify, prioritize, and affirm what they perceive as significant. It provides a hoping person with an incentive to cope effectively with the stressors; it acts as a reference point to evaluate one’s progress. During the process of hoping for a particular hope, other potential hopes can be identified that may assist in relinquishing unrealistic hopes and to establish new hopes. These two spheres contain analytically distinct but overlapping dimensions of hope, which when considered together form the “gestalt” of hope (Dufault & Martocchio).

The *affective* dimension focuses on the sensations and emotions that are part of the hoping process. It encompasses feelings, both comforting and painful, that determine the hoping process. The *cognitive* dimension focuses on the processes by which individuals wish, perceive, interpret, and judge in relation to hope. The hoping person examines a situation and identifies his/her resources and limitations in relation to hope. This dimension enables the hoping person to maintain his/her hope as realistically as possible. When the hope becomes unrealistic, the hoping person may abandon the hope, modify the original hope, or substitute it with a new hope. The *behavioral* dimension deals with the actions taken by the hoping person in relation to his/her hope. These actions are directed to meet one’s daily demands of living, to revitalize their interests, to care for others, or to adjust one’s personal outlook. The *affiliative* dimension includes components of social interaction, mutuality, attachment and intimacy, other-directedness, and self-transcendence. It is characterized by the relationships with people, God, or other living things. It is dependent upon the actions taken by others in relation to their particular hope. The *temporal* dimension focuses upon the hoping person’s experience of time whereby hope is directed toward a future good, but past and present are also involved in the hoping process. The *contextual* dimension focuses upon life situations,

which may include a situation of an actual or potential loss, and can influence the hope of a hoping person (Dufault & Martocchio, 1985).

The MMH has also been empirically tested; several researchers have integrated the MMH into their research practice. In fact, based on the Dufault and Martocchio (1985) MMH, Herth (1990) developed a “Herth Hope Scale.” This 30-item scale reflects the six dimensions of hope as described in the MMH. To increase the clinical usefulness of this scale, Herth (1992) modified Herth Hope Scale to “Herth Hope Index,” which is a shortened version of the initial scale. This revised tool is a 12-item scale that has been used by several researchers and has developed good reliability ($r = 0.91$) and validity ($r = 0.92$) (Herth, 1992).

FACTORS DETERMINING HOPE IN CANCER PATIENTS

Several researchers have explored the concept of hope in palliative care patients and have identified key factors that determine the level of hope in cancer patients. Considering the MMH, Miller (2007) has outlined a few antecedents of hope and threats to hope in cancer patients. These antecedents may include a stressful stimulus such as loss, suffering, and/or uncertainty. Connectedness with God and positive personal attributes that may include one’s philosophy of life and a sense of meaning and optimism can also be considered as antecedents to hope. The threats to hope, according to Miller, include pain or other uncontrolled symptoms, spiritual distress, fatigue, anxiety, social isolation, or loneliness.

Rusteon and Wiklund (2000) have explored the association of variables such as time since diagnosis, type of cancer, treatment, age, gender, and cohabitation status with hope in patients with cancer using an intervention study. The Nowotny Hope Scale was used to measure hope in 131 Norwegian patients with cancer. The study revealed cohabitant status as the only significant factor that determined hope in these patients ($p = 0.005$). People who lived alone had less hope than patients who lived with someone else. Age correlated with hope only on the “spiritual beliefs” subscale and implied that older patients were more inclined to use religion as one of the factors to foster hope. Gender, time since diagnosis, and treatment had no impact on the levels of hope in these patients. This finding is supported by Chen (2003) who examined the effect of disease status and pain on the levels of hope in cancer patients. Two hundred and twenty-six patients with various cancer diagnoses completed the Herth Hope Index. The Pain Assessment Form was used to determine the sensory characteristics of pain and Perceived

Meanings of Cancer Pain Inventory was used to measure the meanings that patients with cancer ascribed to their pain. The findings of this study indicate that perceived treatment effect, not disease stage, significantly influenced the hope level of patients with cancer.

IDENTIFYING THE DETERMINANTS OF HOPE IN MR. A USING THE MMH

Mr. A's hope was not the result of single act but was a blend of complex and varied thoughts, feelings, and actions that changed with time. Mr. A's expression of "I am not giving up" was an outlook that made his living worthwhile. Considering his debilitating life situation, it was his generalized hope that motivated Mr. A to be optimistic and enabled him to carry on with his life's responsibilities. Mr. A was able to set his particularized hope by acknowledging his current life situation and by prioritizing his future needs. Mr. A's particularized hope was characterized by his expectation to have his pain managed and to travel to England. Mr. A's dimensions of hope were evident at various instances and were based on his beliefs that were important to his well-being. Mr. A was diagnosed with metastatic cancer in France (temporal and contextual domains). The uncertainty of his disease status and its outcome made him anxious (affective and contextual domains). Mr. A was provided with additional information by the oncology and palliative team at JBMH that enabled him to conduct a reality scan, to understand his life situation and to plan realistically possible goals (affiliative domain). Mr. A made a reality-based assessment of his disease (pain, nausea, vomiting); identified its impact on his functional status (limited life expectancy, decreased QOL); and explored his resources, i.e. the support of his partner and financial security (contextual and cognitive domains). Based on this assessment, Mr. A was able to set realistic goals to improve his current situation and was motivated to achieve them (cognitive, temporal, and affective domains).

To meet his hopes, Mr. A received Vitamin C infusions; managed his disease symptoms, and decided to spend quality time with his partner. After a short admission to hospital to stabilize his symptoms, Mr. A was able to travel to England. He had a plan in place including extra medications for each of his symptoms. His partner was very committed and supportive of his decision.

APPLICATION OF THE MMH TO NURSING PRACTICE

This model is relevant to nursing practice because nurses are the primary caregivers for terminally-ill

patients and are in a strategic position to enhance or diminish their levels of hope (Herth, 1990). Understanding the spheres and dimensions of hope can enable nurses to be sources of hope for patients in their last days of life (Dufault & Martocchio, 1985). The affective domain of MMH directs nurses to be attentive to patients' emotions and sensations. This can be facilitated by allowing patients to express how and why hope is significant to them, and conveys to nurses the importance of being empathic to patients' worries, fears, and doubts. The cognitive dimension enables nurses to clarify the perception of hope with their patients and to correct any misinformation they may have about the disease or its prognosis. The behavioral dimension can be facilitated by assisting patients to rely upon their resources and those of others in relation to their hope. Enhancing the self-esteem of patients and diminishing their feelings of helplessness can also foster hope. Within the affiliative dimension, nurses can provide information about how others (family, friends, or health professionals) can serve as a source of hope to patients. The temporal dimension directs nurses to be attentive to patients' experience of time; they can determine the sources of hope in patients in the present situation along with their hopes for the future. In the contextual dimension, nurses can assess the life situation that has a particular influence upon hope in patients. Nursing strategies can be directed toward communicating about desired goals, readjustment of plans, and reviewing the values of their patients (Dufault & Martocchio, 1985).

The first step that nurses can initiate to maintain or enhance hope in their patients is to assess their level of hope. According to Herth and Cutcliffe (2002), the clinicians can act as an instrument to assess and foster hope in their patients. Miller (as cited in Herth & Cutcliffe, 2002, p. 981) suggests using a one-item rating scale to rate the level of hope in patients. This type of scale can, however, be very subjective and might not indicate the factors affecting patients' hope, therefore making it difficult for the health professionals to apply specific hope-fostering interventions. Therefore, nurses can utilize a scale such as the Herth Hope Index, which has been used to determine hope in terminally-ill patients (Herth, 1992). The use of this scale in clinical practice can enable nurses to identify factors that may affect the level of hope in patients. The Herth Hope Index can also direct nurses to consider specific hope-fostering strategies for their patients. In addition to using tools to assess hope, nurses can also focus on the nonverbal clues of the patient. For instance, the signs of diminished hope may include a slower response to a request, a dull expression in the eyes, or a dejected tone of the voice (Herth, 1992). This

combination of methods may prove more effective while measuring hope in patients as it was in the case of Mr. A.

The palliative team at JBMH asked Mr. A to rate his level of hope from 1–10, where 1 indicated hopelessness and 10 reflected hopefulness. The palliative team also actively listened to Mr. A's issues and allowed him to talk about his hopes. This in turn enabled the palliative team to identify factors (pain, nausea, and vomiting) that diminished his hope. This type of assessment can enable nurses to identify strategies that foster hope in palliative care patients.

Several researchers, as indicated earlier, have identified various factors that influenced hope in terminally-ill patients (Chen, 2003; Felder, 2004; Herth, 1990; Miller, 2007; Rusteon & Wiklund, 2000). Understanding these factors can enable nurses to mobilize hope resources for their patients. The themes in these studies that were critical in maintaining hope include having a connectedness with significant family members, friends, and/or caregivers; maintaining a spiritual connectedness; and the support or presence of a significant caregiver. These factors can enable a terminally-ill patient to envision his/her future moments of happiness, fulfillment, and connection (Miller, 2007). Miller also emphasized maximizing routine experiences that may be particularly helpful in end-of-life care. Such experiences may include providing favorite food, enjoying the warmth of the sun, listening to music, or even reading a book to the dying person.

In addition to inspiring hope in patients, nurses can also avoid certain hope-hindering practices that have been identified in a few studies (Chen, 2003; Felder, 2004; Herth, 1990; Miller, 2007; Rusteon & Wiklund, 2000). Uncontrolled symptoms, especially pain; abandonment and loneliness; devaluation of personhood; and negative hospital experiences can diminish hope in dying patients. Also, imparting information to the patient in a disrespectful or cold manner; being unconcerned about a patient's situation; or giving discouraging medical facts without offering any assistance can shatter hope in dying patients and thus should be avoided (Felder, 2004).

LITERATURE GAPS

Whereas many researchers would suggest that hope is one of the core values of healthcare culture (Herth, 1990), most "hope researchers" would agree that this phenomenon is under-researched and under-utilized as a therapeutic intervention (Herth, 1990, 1992). Although few studies have explored the phenomenon of hope in terminally-ill patients, it is important to consider that most of these studies are descriptive in nature, therefore resulting in weaker evidence.

The authors realize that the randomized controlled trial might not be the best way to understand hope. However, to understand the efficacy of specific hope-hindering and hope-fostering strategies, one may want to consider various aspects of qualitative and/or quantitative designs. Also, most of the studies highlighted throughout the article are from English speaking countries; therefore, the findings drawn from these studies might not be applicable to other countries and cultures. Therefore further research is required in this domain.

Although the concept of hope has been discussed in the healthcare literature for decades, it is still difficult to find one definition that encapsulates the overall meaning of hope. Most of the reviewed studies lacked synthesis with other models of hope and a few studies clearly lacked a sense of logical sequence. Most of the nursing literature on hope did not explicitly state that their study was an attempt to build upon or add on to the previous body of knowledge. Therefore, there is a distinct need for nurses to purposefully expand the theory around the concept of hope. Researchers need to focus on the interventions based on theory and test them for their empirical effectiveness with a variety of patient populations. Most of all, knowing that nurses are the key to inspiring and promoting hope for those in care, researchers need to gain a better understanding of what hope means to nurses and what significance it has in their nursing practice.

CONCLUSION

Most terminally-ill patients require hope to maintain their dignity, to cope with their stressors, and to enhance their QOL. The MMH explains the concept of hope in the form of two spheres and six dimensions. The MMH has contributed significantly to the depth and breadth of our current knowledge base of hope in palliative settings. However, there is a need to conduct further research studies. These studies will enhance the understanding of what is already known and will fill in the existing gaps. Also, more research studies need to be directed toward the validation of interventions that foster hope in terminally-ill patients. Overall, there is a definitive and rigorous need to incorporate the concept of "hope" in nursing practice.

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