Engendering hope in the chronically and terminally ill: Nursing interventions

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Abstract

Nurses assume a primary role in the care of chronic and terminally ill individuals in their homes and are in a strategic position to foster or hinder hope. Using a descriptive survey design, home health care nurses and hospice nurses were asked to rate proposed hope interventions as to use and effectiveness in facilitating hope in their chronically ill and terminally ill clients. One hundred and fifty-eight registered nurses, representative of six hospice agencies and six home care agencies in a Midwestern state, completed the Hope Intervention Questionnaire. Provision of comfort and pain relief emerged as the most effective and most frequently used hope interventions by both the home health care nurses and the hospice nurses. The top 15 interventions, though ranked in slightly different order, were the same for hospice nurses and the home health care nurses and were reflective of the multidimensions of hope. The findings of this study have practical importance to nursing practice as they provide a framework for selecting strategies to foster hope in the chronically ill and terminally ill population.

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Introduction

Hope is complex, multidimensional, and dynamic; its physical and psychological value as a healing force is gaining recognition. Studies support that hope is important in coping specifically during times of loss, suffering, and uncertainty. It is postulated that "hope may influence how the individual perceives threat to self or goals (antecedent); may enable the individual to appraise the situation as challenging as opposed to threatening (coping strategy); or may help the person to use adaptive tasks and coping strategies that facilitate expanded, as opposed to constricted, functioning (outcome)."[4] Hope is also described as an essential component in enhancing quality of life.[5-7]

Our understanding of the concept of hope continues to grow. Four central attributes of hope have been proposed by Farran, Wilken, and Popovich[8] based on their critical analysis of data on hope from philosophy, theology, nursing, medicine, psychology, and sociology. These hope

attributes include:

- an experiential process;
- a spiritual or transcendent process;
- a rational thought process;
- a relational process.

The role of nurses in engendering hope in their clients is well documented in the literature.

The experiential process of hope involves accepting human "trials" as integral parts of self but allowing a creative and imaginative process to widen the boundaries of the possible. The spiritual or transcendent process involves a sense of faith or certainty about something that has not yet been proven and the transformation of the present reality into one of greater aliveness. The rational thought attribute of hope involves setting of goals, attaining resources, establishing a sense of one's past, present, and future, and maintaining a delicate balance of control. The relational attribute of hope involves the development of a feeling of interconnectedness with others. Farran, Herth, and Popovich[14] suggest that "hope constitutes a delicate balance of experiencing the pain of difficult life experiences, sensing an interconnectedness with others, drawing upon one's spiritual, or transcendent nature, and maintaining a rational or mindful approach for responding to these life experiences."

The role of nurses in engendering hope in their clients is well documented in the literature.[9-11] However, despite recognition of the significance of the nurse's role in enabling hope and the development of instruments to measure hope,[12-16] little evidence has been derived from clinical research to guide nurses in selecting appropriate strategies to mobilize, enhance, and support hope or to prevent or diminish hopelessness.[17, 18] Miller [19] states that "the challenge of nursing is to understand hope in depth and to use deliberate strategies to develop and maintain a generalized hope-filled state in patients and their families."

In the past decade, qualitative studies of hope in healthy and ill individuals and their care givers (*i.e.* family/nurses) have identified potential hope fostering strategies. The studies have involved children and adolescents,[20, 21] older adults,[22, 23] critically ill adults,[24] chronically ill adults,[25, 26] mentally ill older adults,[27, 28] terminally ill adults,[9, 29, 30] and family care givers of the terminally ill.[31] These research findings have provided a preliminary framework for selecting or developing strategies to foster hope and prevent or diminish hopelessness in ill adults and adolescents. In addition, qualitative studies have laid the groundwork for future intervention studies in clinical populations.

The first attempt to classify potential interventions related to hope was completed by McCloskey and Bulechek[32] in the Iowa Nursing Intervention Classification System Project. Nursing interventions designed to promote instillation of hope are delineated within this classification system, however, the use and perceived effectiveness of these activities have yet to be validated by clinical nurses. Wake and Miller [33] compared nursing interventions used to treat hopelessness by critical care nurses in Belgium, Canada, England, France, and the United States. These investigators found many similarities and very few differences in the strategies used by the nurses to engender hope.

The most common strategies identified by all nurses, irrespective of country of origin, were the use of positive communication and the provision of family support. The questions remain, however, as to what hope engendering strategies are used by nurses working in the home situation with chronically and terminally ill patients, how effective are these strategies, and how do these strategies differ from Wake and Miller's reported findings on persons with acute reversible life-threatening illnesses in the hospital.

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Studies suggest that chronic illness differs from acute illness in that it is ongoing, often unpredictable, and symptom severity fluctuates frequently. Chronic illness often assaults one's sense of competence and may impair permanently one's body image. Chronic illness also differs from terminal illness by having no known end in sight. Terminal illness involves a relentless loss of function ending in death.

Hall,[29] in studying individuals with HIV in Stage II, describes the underlying dilemma of hope for the diagnosed terminally ill person as "how to establish an inextricable interconnection between the present and the future and a strong feeling of optimism often in the face of dire predictions." Might nurses working in the home situation with chronically ill or dying clients pose strategies that place an emphasis on comfort, dignity, and transcendence? No studies are reported in the literature addressing, from the perspective of the nurse, the use or effectiveness of specific interventions designed to engender hope in the chronically or terminally ill individuals in their homes. The findings are important to nursing because nurses often assume a primary role in the care of the chronically and terminally ill individual in the home and are in strategic positions to foster or hinder hope.

Methodology

The purpose of this study was to identify and compare the use and effectiveness of hope-engendering interventions employed by hospice nurses and home health care nurses in their care of terminally ill and chronically ill clients respectively.

Design

Using a descriptive survey design, home health care nurses and home care hospice nurses were asked to rate proposed hope interventions as to use and effectiveness in facilitating hope in their chronically ill and terminally ill clients respectively. In addition these nurses were asked to estimate how often they used these interventions in practice.

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Setting and Sample

The study was conducted at six hospice agencies and six home care agencies representative of rural, urban, and metropolitan areas in a Midwestern state. A convenience sample of 62 registered nurses working in the hospice setting, and 96 home health care registered nurses working through a home health agency, was drawn from an accessible population of 162 registered nurses. Institutional Review Board (IRB) was obtained from the appropriate agencies. Participation in the study was voluntary. Contact of potential registered nurse subjects was made through placement of both a letter explaining the nature of the study, and the Hope Intervention Questionnaire, in all registered nurses' mail boxes within their places of employment by the investigator. An enclosed postage-paid envelope was included so that the participants could return their questionnaires and instruments directly to the investigator. Completion and return of the questionnaire was interpreted as implied consent.

Findings

Characteristics of the Study Sample

One hundred and fifty-eight registered nurses completed the questionnaire. Fifty two of the 62 hospice nurses (83 percent) and 76 of the 96 home health care nurses (79 percent) who completed the study were females. Ages ranged from 20 to 61 years old, 40 percent (N= 63) were between the ages of 30 to 39 years old, with a mean age of 36 years old.

Twenty-five percent (n=15) of the hospice registered nurses and 28 percent (n=29) of the home health care registered nurses held an Associate of Science Degree in Nursing or a Diploma in Nursing. Fifteen percent (n=9) of the hospice registered nurses and 14 percent (n=13) of the home health care registered nurses held a master's degree.

Experience in home health care ranged from three months to 24 years, with a mean of eight years, and a median of seven years. Specific experience in hospice nursing ranged from six months to six years, with a mean of 4.4 years, and a median of 4.2 years.

Chronic illness diagnoses represented in the clients cared for by the home health care nurses ranged from unstable diabetes and congestive heart failure to cancer and AIDS. The majority (88 percent) of the clients cared for in the hospice care program had terminal cancer, 2 percent were in the final stage of AIDS, and 10 percent had end stage cardiac, neurological, or respiratory conditions.

Instrumentation

The instrument used in this study, the Hope Intervention Questionnaire (HIQ), was developed by the investigator. A comprehensive review of literature on hope was undertaken to identify potential interventions. Specific note was taken of hope enhancing strategies identified in qualitative studies within the literature. For the pur-

Table 1. Rank order of hope inspiring intervention effectiveness for interventions identified by hospice nurses (N = 62) and home health care nurses (N = 96)

	Hospice Nurses				Home health care nurses			
Intervention	$\overline{X}$	SD	Certainty level	Rank	$\overline{X}$	SD	Certainty Level	Rank
Provide comfort/pain relief[4]	4.762	.529	99.8%	1	4.692	.573	91.0%	1
Facilitate a sense of sustained connectedness with others[2]	4.725	.673	98.6%	2	4.296	.522	94.2%	4
Help to see positive small joys in the present[1]	4.689	.462	90.0%	3	4.151	.742	89.8%	10
Help redefine hope when specific hopes not attanied[4]	4.662	.843	97.2%	4	4.028	.655	89.0%	5
Facilitate expression of spiritual beliefs and practices[3]	4.248	.782	88.0%	5	3.674	.598	87.8%	7
Assist to identify areas of hope in life[1]	4.200	.699	89.4%	6	4.522	.541	94.0%	11
Support & engender hope in significant others/family[2]	3.961	.824	91.1%	7	3.797	.359	86.0%	9
Engender a sense of lightheartedness[4]	3.923	.998	91.5%	8	4.667	.623	98.2%	2
Assist to devise and revise manageable or stepwise goals[4]	3.800	.760	85.0%	9	4.587	.713	95.6%	14
Communicate verbally and nonverbally own sense of hope[4]	3.796	.488	94.2%	10	3.998	.866	88.0%	12
Encourage to share about their hopes and fears[1]	3.684	.941	96.1%	11	4.449	.428	97.0%	6
Help to take each day as it comes[4]	3.652	.753	92.0%	12	3.887	.711	88.0%	13
Assist to regain/maintain interest in hobbies, projects, family[2]	3.599	.998	94.6%	13	4.238	.321	88.4%	8
Involve actively in own care/progress[4]	3.548	.759	90.2%	14	4.622	.597	96.0%	3
Share positive and inspiring stories[4]	3.521	.655	84.1%	15	4.431	.467	94.0%	15

Notes: [1] Experiential process; [2] Relational process; [3] Spiritual/transcendental process; [4] Rational thought process

poses of this study, hope as defined by Dufault and Martocchio,[34] served as the guiding framework. Hope is "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which, to the hoping person, is realistically possible and personally significant."[35] Within this framework, hope is viewed as having both a global and time specific focus and as having multiple dimensions of which some dimension is always present within the individual.[12]

The conceptual framework for the instrument was based on the four central attributes of hope (experiential, spiritual/transcendent, rational thought, and relational). Interventions were categorized according to these attributes so that there was equal representation of each of these attributes. A panel of experts reviewed each intervention on the HIQ for logical consistency with one of the four attributes of hope and with the definition of hope given by Dufault and Martocchio. If each of these criteria was met by 98 percent agreement, the intervention was added to the instrument.

The final HIQ was a 46-item, Likert-type, self-report instrument. Proposed hope interventions were listed and the subjects were asked to rate each item in two columns: the first rating how often they used the intervention in practice and the second rating how effective the intervention was in helping clients attain and/or maintain hope. Subjects were directed to circle U if they were uncertain of their response. A five-point scale was used, with one indicating the least effectiveness and lowest frequency of use, and five designating the highest effectiveness and frequency of use. Internal consistency reliability (Cronbach's alpha) with this sample was .92 for the effectiveness scale and .90 for the frequency scale.

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Open-ended questions were used to ask subjects to identify other interventions they used to facilitate hope. Subjects were also asked to identify how important they believed hope was to those they cared for in their practice by means of a single question with a five-point response form (one = not important, five = highly important).

Results

Significance of hope. Subjects identified that hope was highly important (X=4.56) to those they cared for in their practice. Hospice nurses' mean score on importance of hope was lower (X=4.35) than that of the home health care nurses (X=4.78) though not statistically significant. None rated hope to be of minimal or no importance.

Intervention effectiveness and use. All interventions listed on the HIQ were rated three or above on the five-point effectiveness scale by 89 percent (n = 141) of the subjects. At least one-half of the subjects rated 24 of the interventions as both effective in facilitating hope and used at least some of the time in their practice. Of the 15 highest rated effective interventions, subjects indicated a certainty level of at least 91 percent. No additional interventions were suggested by the subjects.

Tables 1 (previous page) and 2 (following page) show the ranking order of the top 15 hope interventions rated as most effective and most frequently used. The five top-rated interventions for being the most effective and most frequently used by the hospice care nurses were:

- to provide comfort/pain relief;
- to facilitate a sense of sustained connectedness with others;
- to help to see the positive small joys in the present;
- to assist to redefine their hopes;
- to facilitate expression of spiritual beliefs and practices.

For home health-care nurses the five top-rated interventions were:

- to provide comfort/pain relief;
- to assist to devise and revise manageable or step wise goals;
- to involve actively in own care/progress;
- to facilitate a sense of sustained connectedness with others;
- to help redefine hope when specific hopes were not attained.

Provision of comfort and pain relief was rated as the most effective and most frequently used interven-

Table 2. Rank order of frequency of hope-inspiring intervention use for 15 interventions most frequently used by hospice nurses (N = 62) and home health care nurses (N = 96)

	Hospice nurses		Home health care nurses	
Intervention	$\overline{X}$	Rank	$\overline{X}$	Rank
Provide comfort/pain relief[4]	4.982	1	4.653	1
Facilitate a sense of sustained connectedness with others[2]	4.814	2	3.973	3
Help to see positive small joys in the present[1]	4.800	3	4.442	7
Support & engender hope in significant others/family[2]	4.796	4	4.426	13
Facilitate expression of spiritual beliefs and practices[3]	4.788	5	3.445	15
Help redefine hope when specific hopes not attained[4]	4.708	6	4.112	5
Help to take each day as it comes[4]	4.593	7	4.086	12
Encourage to share about their hopes and fears[1]	4.276	8	3.821	14
Share positive and inspiring stories[4]	4.182	9	4.502	6
Assist to identify areas of hope in life[1]	3.822	10	4.634	11
Assist to devise and revise manageable or stepwise goals[4]	3.800	11	4.628	2
Communicate verbally and nonverbally own sense of hope[4]	3.764	12	4.573	10
Involve actively in own care/progress[4]	3.695	13	4.599	4
Assist to regain/maintain interest in hobbies, projects, family[2]	3.618	14	4.293	8
Engender a sense of lightheartedness[4]	3.549	15	4.387	9

Notes: [1] Experiential process; [2] Relational process; [3] Spiritual/Transcendent process; [4] Rational thought process

tion, with both hospice nurses and home health care nurses indicating 100 percent certainty.

Comparison of effectiveness with frequency of use. With four exceptions, subjects rated interventions that they considered most effective as the interventions that were most frequently used in practice. Massage, therapeutic touch, and exercise were the interventions that were most infrequently used or believed least effective in engendering hope in the clients cared for by both hospice nurses and home health care nurses.

Discussion

This is the first study to ask the nurses themselves to evaluate the use and effectiveness of hope interventions. Both home health care nurses and hospice nurses identified that hope was highly important to those they care for in their practice and therefore should be a priority in their clinical practice. The top five interventions identified by both the home health care and hospice nurse were consistent with hope enhancing strategies identified in qualitative studies with elderly, critically, chronically, and terminally ill indioviduals.[9,23,24,34] The four attributes of hope (experiential, spiritual/transcendental, relational, and rational thought) were represented in the five highest-rated interventions for both use and effectiveness by hospice nurses. In contrast, only interventions reflective of the rational thought attribute of hope were

ranked by home health care nurses in the top five for both use and effectivenss. This may reflect the fact that those who are chronically ill must continually deal with the ups and downs that occur during the long trajectory of living with a chronic illness.

Research studies have consistently identified the importance of cognitive strategies to the enhancement of hope in those experiencing fluctuations in symptoms.[36-38] In a qualitative study of eight men infected with the HIV virus, Hall[39] found that cognitive strategies enabled those individuals to regain a measure of hope. This is further supported in a study by Owen[29] in which clinical nurse specialists described hopeful cancer patients as those who had definite goals but were able to change their goals as their condition worsened (rationale thought attribute of hope). Other studies have identified that helping clients determine manageable or stepwise goals may create a sense of attainment in individuals lacking hope.[26,40]

Comfort and pain relief emerged as the most effective and the most frequently used hope intervention by all study participants. This finding is consistent with qualative research data that identified poorly controlled symptom and pain management in older adults,[23] critically ill adults,[24] adults with cancer,[41] and terminally ill adults[9] as a hindrance to attaining or maintaining hope. It is postulated that pain and symptom control will influence positively an individual's hope. In a multinational study of hope,[33] nurses from Belgium, Columbia, and Canada were the only nurses to emphasize physical comfort as a strategy to enhance hope. Please note that the importance of pain control on hope in this study may be reflective of pain management being a central tenant in hospice programs.

The findings of this study have practical importance to nursing practice as they provide a framework for selecting strategies to foster hope in the chronically ill and terminally ill population.

Connectedness with others was ranked number two by hospice nurses and number four by home health-care nurses in both use and effectiveness in this study. Open, caring relationships have been identified as crucial to the mobilization, support, and maintenance of hope and prevention of hopelessness in studies of adults, adolescents, critically ill adults, older adults, and terminally ill adults in the United States.[9,11,23,38] Positive interpersonal relationships have also been emphasized by nurses in Belgium, Canada, Columbia, England, and France.[33] This importance of connectedness is also evident in findings related to caregivers. In a recent study by Farran, Salloway, Kupferer, and Wilken,[22] the most frequently noted attribute of hope identified by caregivers of persons with dementia were their relationships with family members and their experience of their care recipients' love that gave them hope and kept them going (relational process).

Facilitation of the client in the expression of spiritual beliefs and practices was ranked number five by the hospice nurses in both use and effectiveness and number seven in effectiveness and number 15 in use by the home health care nurses. Qualitative studies have supported the spiritual nature of hope.[42-44] Raleigh[45] in her study of 45 individuals with cancer and 45 individuals with other chronic illnesses found that the most commonly supported sources of hope were family, friends, and religious beliefs. Wake and Miller's[33] multinational study of hope-inspiring strategies found that US nurses were the only respondents suggesting spiritual strategies as a means of fostering hope. It is interesting to note that the hospice nurses facilitated the client's expression of spiritual beliefs and practices to a greater extent than home health care nurses, though both groups felt the strategy was very effective in helping the clients to attain or maintain their hope. This finding may reflect the basic hospice tenant that places emphasis on spiritual care of the client as well as the physical, emotional, and social care.

Research studies, including the present study, consistently identify the importance of goal setting and goal refinement to the enhancement of hope.[24,46,47] Both hospice and home health care nurses rated assisting clients to redefine their goals (hopes) when specific goals (hopes) are not attained as a high in effectiveness, and as a strategy used by the nurses.

Interestingly, the top 15 interventions, though ranked in slightly different order were identical for hospice nurses and home health care nurses and were reflective of the four attributes of hope. This further supports the multidimesions of hope.

Implications for nurses

The findings of this study have practical importance to nursing practice as they provide a framework for selecting strategies to foster hope in the chronically ill and terminally ill population. Helping clients achieve hope that is independent of life events is a challenging but important nursing task. It can bring a sense of well-being to clients and improve their quality of life.

The 15 top ranked interventions provide the nurse with a preliminary guide from which appropriate interventions to engender hope can be selected for the individual client. For example, armed with the knowledge that comfort and pain relief may influence a client's hope level, the nurse can concentrate initial efforts in the care of the chronically or terminally ill client on implementing strategies that will lead to achievement of pain relief and comfort. It may be that no other concerns are perceived as important by the client until pain and other distressing symptoms are controlled; it is only then that hope can emerge. Once comfort is achieved, the chronically ill may need assistance, guidance, and support with identification of areas of hope in life and with goal development or revision. The hospice client, however, may need assistance in forming or maintaining a sense of connectedness with others.

Nurses can serve as catalysts to create internal and external conditions that foster caring relationships between clients and their families, friends, and other professional caregivers and can assist the person to see small joys worthy of celebration.

If spiritual beliefs are important to the client's hopes, nurses may need to facilitate an environment and the resources necessary to express spiritual beliefs and practices. In this study, home health care nurses were hesitant in their use of interventions that addressed spiritual needs, however, they expressed the belief that these interventions did enhance hope in their clients.

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The current study adds further support to the recent work on the importance and potentially therapeutic role of humor.[48,49] Lightheartedness (humor) was identified as effective in engendering hope by both hospice and home health care nurses, though not as often used by the hospice nurses as by home health care nurses. It may be that terminal illness connotes an attitude of seriousness, not one that allows or invites lightheartedness, thus hospice nurses have difficulty initiating humor. The hospice nurses in this study, however, recognized the potential therapeutic value of humor on hope in terminally ill clients. Studies support that fostering lightheartedness through the appropriate use of humor may enable the emergence of hope.[9,50]

Future Direction

Replication of the study with other nursing populations will be important to evaluate the centrality of pain control and symptom management to hope. Well-defined intervention studies are needed to test the efficacy of various nursing interventions designed to strengthen hope.

More research is needed to expand the theoretical base for hope nursing interventions.[51] Attention needs to be given to testing the effectiveness of specific interventions to enable hope across ethnic, cultural, and national boundaries. Comparative studies determining reliability and effectiveness of methodologies across various client populations and across the developmental age span need to be undertaken. Need also exists for the development and testing of a tool to measure hope maintaining strategies and to measure the relationship between maintaining hope and outcomes of treatment. Future research is indicated to determine which interventions are effective and which are not, and whether all strategies apply to all patients or whether some are more effective in some clients than others. In addition, methods need to be developed to systematically implement and measure hope-inspiring interventions over time. This research study provides a beginning identification of nursing interventions that the nurse might select to engender hope in their terminally ill and chronically ill clients in the home setting.

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