

The Meaning of Hope for Patients Coping with a Terminal Illness: A Review of Literature

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Abstract

Purpose: A comprehensive review of literature was completed to examine available research on the concept of hope for patients with a terminal illness and how hope influences the coping process.

Method: An electronic search of CINAHL, OVID MEDLINE and Google Scholar using relevant was conducted. This produced 12 pertinent articles, 5 of which were primary research studies that investigated the concept of hope for patients with terminal disease. Study eligibility criteria included research on hope and participants facing a potentially terminal illness. Study design, sample size, characteristics of the subjects, and assessment tools for the 5 primary research studies were also identified. Overarching, consistent themes and findings were identified for the majority of articles.

Findings: Hope is a central issue for patients facing a terminal illness. The topic is fairly well studied; however, all 5 research studies pertinent to this area of study were conducted outside the United States. The three major themes that emerged were barriers to hoping, hopelessness and goal setting for patients diagnosed with a terminal illness.

Conclusion: Additional research on the meaning of hope for patients with a terminal illness is needed in varying environments, including hospitals, homes and/or hospice care. Also, more research is needed to understand how having hope is a part of the coping process for this patient population. Finally, the role of health care professionals in facilitating hope needed further research in order to enhance patients' well being.

Keywords: Terminal illness; Coping; Hope; Hopelessness; Adaptation/psychological; Spiritual; Spiritual well being; End of life; Living in hope; Herth hope index

Introduction

Hope, as a concept, both separate from and within health care has been widely researched (Hammer et al. [1]; Miller [2]; Lin and Bauer-Wu [3]; Everson et al. [4]; Ripamonti et al. [5]) [1-5]. Under this umbrella of hope, research has also been conducted on what patients hope for following a terminal diagnosis (Miller [2]; Lin and Bauer-Wu [3]; Benzein et al. [6]) [2,3,6]. Miller [2] emphasized that "Hope is central to life and specifically is an essential dimension for successfully dealing with illness and for preparing for death" (p. 12). However, throughout the literature, a plethora of definitions, implications of and possible uses for hope exist. Because of the subjective nature of hope and various words used to describe the experience and potential benefits, it may be difficult for readers of the literature, health care professionals and patients to procure the role for hope when faced with a terminal illness. Thus, further research into the relationship between hope and coping for patients diagnosed with a terminal disease would likely add to the body of existing literature on this topic. The aim of this literature review is to answer this question: What does the concept of hope mean to patients diagnosed with a terminal illness? Furthermore, how does patients' understanding or perspective of hope help them to cope with their diagnosis?

Method

Sample

A comprehensive review of literature was conducted throughout the months of September and October 2012. Databases used included Ovid MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Google Scholar. Keywords for searching these databases included: terminal illness, coping, hope, hopelessness, adaptation/psychological, spiritual, spiritual well being, end of life, living in hope, and Herth Hope Index. The time frame for this literature

review spanned from 1992-2012. The most productive search was completed in CINAHL using keywords: terminal illness, coping and hope. Using these inclusion criteria, 36 articles were retrieved. Articles were excluded if the population studied was not patient-centered. Second, studies were excluded if the patient population was not diagnosed with a terminal illness. Last, articles were excluded if there was not an accessible electronic file for these potentially applicable articles. A total of 12 articles were chosen to study extensively for the review of literature with 5 research articles pertinent to the topic found.

Procedure

Using the Matrix Method (Garrard [7]), the 12 articles were read thoroughly in chronological order. Each article was assessed for the following qualities: type of article, abstract, purpose of research, study design, results and major issues and themes discussed. Three major types of articles were found: theoretical models (Bergin and Walsh [8]; Gum and Snyder [9]) [8,9], literature reviews (Hammer et al. [1]; Lin and Bauer-Wu [3]; Kylmä et al.) [1,3,10] and research studies (Table 1).

Empirical research

The 5 research studies found and reviewed were all conducted outside the United States. The number of studies within the states was not plentiful, revealing a need for further research within the U.S. on this topic. The reviewed research was conducted in four countries: Sweden,

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Author, Year	Purpose	Sample Size and Population	Setting	Methods	Results
Everson et al. [4], 1996	To examine the relationship between levels of hopelessness and mortality	2428 Middle-aged men, ages 42-60, with previously unestablished but promising risk factors for carotid atherosclerosis, IHD and other outcomes in Eastern Finland	Outpatient	Population-based (longitudinal)	Hopelessness is a predictor of adverse health outcomes, independent of behavioral, psychosocial or sociodemographic risk factors.
Benzein et al. [6], 2001	To uncover the importance of the lived experience of hope for patients with cancer	4 women and 7 men, ages 54-83, with incurable cancer who received palliative care in Sweden	Home care	Qualitative (phenomenological-hermeneutic)	It is possible and important for patients with a terminal cancer diagnosis to have hope; hope is not static. "Living in hope" is central to palliative home care.
Benzein and Berg [11], 2005	To determine the relationship between hope, hopelessness and fatigue	40 patients diagnosed with cancer, receiving palliative care and 45 family and/or social supporters in Sweden	4 in- and outpatient oncology clinics	Instruments (Hope Herth Index—Swedish version [HHI-S] and The hopelessness scale [HS])	Hope is important for patients and their family and/or social supports; nurses need to encourage ways to facilitate experiences of hope for both parties.
Rustoen et al. [12], 2011	To determine the outcome of the hope intervention (HOPE-IN) on levels of hope and psychological distress	194 patients diagnosed with cancer	Norwegian communities	Single group (longitudinal) study using the HOPE-IN	After the HOPE-IN was used, 95% of participants reported HOPE-IN was useful; levels of hope increased and psychological distress decreased.
Ripamonti et al. [5], 2012	To confirm the usefulness of the HHI in Italy for patients with solid or hematological malignancies during cancer treatment	266 patients over the age of 18 diagnosed with non-advanced cancer with life expectancy >6 months	Outpatient	Instruments <ul style="list-style-type: none"> • HHI—The Italian version • Hospital Anxiety and Depression scale (HADS) • FACIT-spiritual well-being scale (FACIT-Sp) • System of Belief Inventory) SBI-15R) • Edmonton Symptom Assessment Scale (ESAS) 	The Italian version of the HHI is valid and reliable; the HHI is a potentially useful tool in the clinical setting to facilitate difficult conversations.

Table 1: Studies addressing the concept of hope for patients with a terminal illness.

Norway, Italy and Finland (Table 1). Various disciplines conducted the studies, including palliative medicine, nursing and psychology.

Everson et al. [4] studied the relationship between hopelessness, mortality and incidence of myocardial infarction and cancer. 2428 middle-aged men used a 2-item questionnaire. The two items included, "I feel that it is impossible to reach the goals I would like to strive for" and "The future seems to me to be hopeless, and I can't believe that things are changing for the better," with responses recorded using a 5-point Linkert scale [4]. Everson et al. [4] was the first to reveal "reliable associations between hopelessness and a broad range of mortality outcomes." Additionally, Everson et al. [4] confirmed previous research concerning an association between hopelessness and poorer survival for patients with cancer. Everson et al. [4] was the first study of this kind and concluded with a call for continuing research on the relationship between hopelessness and mortality for other disease processes as well as additional research on what exactly leads to hopelessness.

Benzein et al. [6] were consistently referred in current research. For this review of literature, their qualitative study will be heavily referred, for it encompasses the highpoints of the other four studies. In this qualitative review, Benzein et al. [6] studied 11 patients diagnosed with terminal cancer who lived at home while receiving palliative care. The aim of the study was to better understand what it meant for this patient population to live out hope. Because there are "few studies aimed at in-depth revelation of the meaning of the lived experience of hope from the perspective of patients with incurable cancer," these researchers were eager to interview patients. Nurses who worked in primary care, hospital-based home care or a palliative care team facilitated narrative interviews for each patient. The nurses began the dialogue with open-ended questions, with the intent of patients sharing whatever it meant to them to live through their diagnosis, specifically what it

meant to experience or not experience hope (p. 119). These narrative interviews were tape recorded, analyzed and interpreted in-depth. The interpretation was completed using a phenomenological-hermeneutic method. Researchers gleaned many important findings from this qualitative study. Namely, Benzein et al. [6] found in their initial reading of the interviews, that more than anything, the first aspect of living in hope is for patients to have "a will to live for a while longer" (p. 119). Within Gum and Snyder's [9] theoretical framework, their hope theory stated that "the person's superordinate goal is survival; to pursue earthly goals, a person must be alive." This highlights a later point of discussion, which is the importance of goal setting for patients with terminal illness, which will be further discussed in detail. Another set of researchers who emphasized the importance of living longer included Hammer et al. [1]. Other key findings delineated from the content analysis in Benzein et al. [6] included a universal awareness of the future with a focus on living in the present (p. 119), taking a fresh look at what was truly important in life, confronting immense feelings of dependency and uncertainty and initiation of thoughts concerning spirituality and the possibility of an afterlife (p. 120). The feelings of uncertainty mainly stemmed from "lack of information, especially about the disease and its prognosis" (p. 120). This is an area where health care professionals have an opportunity to intervene and should be considered. However, there is some debate on whether it is more beneficial to the patient to fully disclose or not fully disclose prognosis (Gum and Snyder) [9]. Gum and Snyder [9] have concluded that, "it is best left to the dying person to judge the goal of survival as being lost or blocked" (p. 886). Again, this is debated throughout the literature and intimately relates to the concept of false hope, which will later be discussed.

Another research study also conducted in Sweden by Benzein and Berg [11] aimed to explore the relationship between hope, hopelessness and fatigue for both patients and their families in the palliative care

setting. These researchers studied 85 participants who completed the Herth Hope Index (HHI) and Beck's Hopelessness Scale. Family members reported having less hope than patients. This result led researchers to conclude that nurses in the palliative care setting need to engage in holistic conversations about hope with both the patient and his/her family members.

Rustoen et al. [12] studied the effectiveness of the HOPE-IN, a hope intervention on patients' levels of hope and their psychological distress at different intervals of time for 194 participants, all of whom had a diagnosis of cancer; most participants were women with breast cancer. Rustoen et al. [12] noted that there was a lacking body of knowledge on the impact that a hope intervention makes on patients' hope and psychological distress despite widely agreed upon research that a cancer diagnosis stimulates psychological distress for patients (p. 352). To their knowledge, this was also the first study of its kind, evaluating how a hope intervention influences patients' hope and psychological distress. The HOPE-IN entailed eight 2-hour sessions over eight weeks, where different topics were discussed, including belief in oneself, relationships, spiritual beliefs and acknowledgement of a future and others (p. 353). Patients' levels of hope were measured at different intervals using the Norwegian version of the HHI and psychological distress was measured using the Impact of Event Scale (IES). 95% of participants self-reported that the HOPE-IN was useful. Additionally, hope increased for these patients and psychological distress diminished following this hope intervention, supporting the researchers' hypothesis. Participants reported a deep appreciation for having the opportunity to congregate with people who were enduring a similar situation, implying the importance of support groups. The researchers' conclusions were that the HOPE-IN was an effective tool and additional research is needed about how to make perfect, the intervention for a variety of patients with different cancer diagnoses.

Ripamonti et al. [5] conducted a study in Italy examining the usefulness of the HHI for patients with solid or hematological malignancies receiving active cancer treatment during the non-advanced stages of their disease process. Ripamonti et al. [5] enrolled 266 patients and all completed the 12 items of the Italian version of the HHI using a 4-point scale to answer the questions. The HHI indicates that there are many aspects to hope; some of these include loving and being loved, spirituality, setting short and long term goals, autonomy, involvement in one's care and humor. On the other hand, isolation, abandonment, depersonalization and lack of management of pain and suffering keep hope from budding. Simply put, this study found that the Italian version of the HHI was valid and reliable and could be used to prompt edifying conversation with patients. Next, three main topics of focus found in the literature will be discussed: hopelessness, barriers to hope, and attainable goal setting.

Discussion

Hopelessness

Throughout the review of literature, much of the most valuable sources were not found until the keyword, hopelessness, was used. Hopelessness was not firmly defined in the literature but was defined in more subjective terms, as was hope. Whether or not hopelessness was defined, the opposite of hope was not found in the literature review. However in her own review of literature, Miller [2] expressed that "Hoping is an oscillation between hope and despair rather than a stable state" (p. 17). She drew from other cited sources that had found that decreased hope was associated with lower quality of life and self-esteem. Hammer et al. [1] also found this relationship between hope,

hopelessness and despair. In their meta-synthesis of the meaning of hope, these researchers discovered a link between these three expressions, naming hope as having a "dialectic" dimension (p. 554, 555). Interestingly, hope, hopelessness and health were found to be intertwined into one unit, "two sides of the same coin," (p. 554) as they put it, "Thus, hope and hopelessness are closely linked to living in fear of dying or other kinds of despair" (p. 554). Similarly to barriers to hope, health care professionals "hold the power to diminish or enhance hope" (Hammer et al., p. 554) [1]. These statements are in line with the study conducted by Everson et al. [4] who found that hopelessness is independently related with cancer deaths. Everson et al. [4] clearly states, "Hopelessness is associated with poorer survival among cancer patients" (p. 119), proving to be the first empirical study at that time to illustrate "reliable associations between hopelessness and a broad range of mortality outcomes" (p. 119) as previously stated.

Barriers to hope

Throughout the literature, there was a vague yet still present focus on what kept patients from hoping. Though the word "barrier" was never specifically found in the literature review, Miller [2] emphasized, "Threats to hope include pain, other uncontrolled symptoms, spiritual distress, fatigue, anxiety, social isolation and loneliness. Perceptions of hopelessness from powerful others (health team, family) also threatens hope" (p. 14). Again, the most pertinent research study related to this issue was Benzein et al. [6]. In their structural analysis of the narrative interviews, these researchers found that patients did not always find it easy to cope and the lived experience of hope rested "on person attributes, such as personality, attitudes, outlook on life and values" (p. 120). Additionally, Benzein and Berg [11] reiterated that fatigue is "the most untreated symptom of cancer and there has been a reluctance to prioritize fatigue and to develop ways to manage it" (p. 238) and that it is essential to be addressed by the health care team. Benzein et al. [6] emphasized that providing pain management, and other symptom control such as for diarrhea and dyspnea for patients with terminal cancer is crucial "in order to make room for hope. The severity of the symptoms is related to the perception of the progress of the cancer" (Benzein et al. p. 124) [6]. It is especially important to address if the patient's concept of hope is categorized as "living in hope" as Benzein et al. [6] described—for this type of definition is more action oriented and fatigue may be a hindrance, though more research is necessary (Benzein and Berg, p. 238) [11]. Gum and Snyder [9] focus on the relationship between Snyder's hope theory's focus setting goals and what may block the way of attaining these. This will be addressed in the following section; however, these researchers make it clear that whatever goal a patient with a terminal illness sets, "When the goal loss or blockage is realized, however, this will have a negative impact on pathways thinking" (p. 886). It is thus important for health care providers, namely nurses, to understand these barriers and to intervene [1,2,6,9-11].

Goals and the role of the nurse

Throughout all of the literature perhaps the most prevalent theme within the concept of hope for patients coping with a terminal illness was having attainable goals set throughout the dying process. Kylmä et al. [10] quoted Dufault and Martocchio (p. 380) [13] who detailed hope as "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving future good, which, to the hoping person, is realistically possible and personally significant" (Kylmä et al., p. 365) [10]. Goal setting is also paramount in the theoretical framework of Gum and Snyder [9]. They went as far as possible to say that "Hope is one such human strength that is implicated in coping

adaptively with the dying process. When hope is present, people can identify meaningful and realistic desired outcomes, and harness the resources for pursuing those outcomes.

“Dying patients are likely to use such active coping, if they are hopeful that their strategies will be effective in reaching their desired goals” (Gum and Snyder, p. 883) [9]. In sum, these theorists highlight that survival is the first and foremost goal (p. 885) but “even if hope for a cure is lost, the person still can maintain hope for other goals that can be attained up to and beyond death” (Gum and Snyder, p. 888) [9]. Whatever these goals may be, Gum and Snyder [9] emphasized the importance that all goals are more likely to yield positive results for patients. Likewise, Benzein et al. [11] found that one hope of terminally ill patients was to live as close to a “normal” life as possible and part of this was establishing goals. Zero of the 11 patients interviewed, mentioned long term goals; all spoke in the short term. Oftentimes goals were formulated in the mornings. As one interviewed patient expressed, “Now I think, I hope I can sit up this afternoon, I’m going to have a visitor, I hope I have the energy” (Gum and Snyder, p. 121) [9]. Confirming this patient’s sentiments, Hammer et al. [1] found that hope has active dimension to it where setting goals and meeting them results in satisfaction, where “Hope is the subjective probability of a good outcome for ourselves or someone close to us, such as hoping for life over death” (Hammer et al., p. 553) [1]. As stated earlier, when this flickering hope for survival is snuffed, there needs to be alternative, attainable goals (Gum and Snyder) [9] and nurses are pivotal in this time (Miller) [2].

One role of nurses during the end of life is to “offer alternative hopes, move from a particularized view to generalized state of being view of hope”, though the “challenge to nurses is great when unrealistic hopes leads to futile therapies, which increase a person’s suffering at the end of life” (Miller, p. 15) [2]. This statement points to the impact of false hopes. The majority of the research reviewed emphasized the meaningfulness of setting goals and is noteworthy for both patients and healthcare providers to be aware of (Hammer et al.) [1]. Goal setting was found most effective when goals were rooted in what physician Basta [14] deemed “true hopes,” which “are based on the truth that there is always more to do for the patient, even when there is nothing more to do from a medical standpoint. Redirecting hope should be an end-of-life goal...” (p. 414). Examples of true hopes included patients’ reconciliation with their pasts and with their relationships. True hopes are home to meaning. Benzein et al. [6] also found that part of the lived experience of hope was “living in hope,” where reconciliation with life and death and the relationships within life were important (p. 123). Restoring broken relationships, shattered pasts and severed spiritual beliefs are important goals for patients that can be truly hopeful (Basta) [14]. Honesty from health care providers, patients and families make this possible. However, false hopes have the potential to “devastate the patient and family” (Basta, p. 414) [14]. Though the hope for a cure is inevitable, once the diagnosis is believed to be terminal, the goal for recovery—the hope to live—takes a turn.

Benzein et al. [6] found that “The hope of being cured was the most significant experience” for patients; despite knowing the odds of survival were low, patients wanted to believe something could help them—a miracle, a new medicine. That something can take on many shapes and the health care providers are a part of encouraging true hopes for patients to strive towards. However, if that something is a false hope, such as a futile chemotherapy regimen or an ignorantly exaggerated prognosis—one is left to wonder if health care providers are encouraging hope or hopelessness. As a physician, Basta [14] witnessed the ramifications of false hopes patients believe: “All too often, I

have seen patients undergoing futile therapy, clinging to false hopes, avoiding hospice, and never finding the true hopes that give death its dignity and meaning” (p. 415). It is the duty of health care providers to support patients coping with a terminal illness. Helping patients form realistic goals, including redirecting their hopes, managing their symptoms effectively and engaging in therapeutic conversation about hope are only a few [2,11,14].

Conclusion and Future Prospects

This review of literature illuminated several conclusions. First, more research is needed on how patients experience hope. Additional research is especially needed for how this concept of hope is or is not a part of the coping process for patients diagnosed with a terminal illness (Rustoen et al.) [12]. The actual word, cope, was not readily used throughout the literature, further warranting the need for additional research. The third dimension of more research needed incorporation of the role of health care providers, specifically nurses, and facilitates hope in this patient population (Hammer et al.) [1]. As Kylmä et al. [10] made clear, more research concerning hope in palliative care is needed in home care, hospital care and/or hospice care as well as with varying age groups and with differing diagnoses, not only cancer (p. 374). Finally, the role of nurses is important [2,9,11] “as hope is a behaviour and everyday concept that is essential for nursing but that is broad and abstract and needs to be described in its volume (Hammer et al.) [1]. When the end of life has come, not all hope is lost, according to the CEO of Hospice of the Piedmont in Charlottesville, Virginia, Dr. James Avery. This physician is a strong supporter of hopeful living and dying. In a recent Charlottesville newspaper article, Dr. Avery expressed that hospice care is centered around hope because, “...This thing called hopes of the dying: that they can die peacefully, that they could die at home, that they could die with love, that they could die having given and received forgiveness, that they could die with their wishes honored, that they could have control over things. Those are the new hopes we are giving them” [15]. Dr. Avery’s hospice is invested in promoting hope for their patients. This review of literature confirms the need for the same investment by researchers, doctors, nurses and other health care professionals for the good of patients battling a terminal illness. Initiating conversation with patients concerning what hope means to them in light of their terminal disease is a place to start.

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