

Published in final edited form as:

Am J Hosp Palliat Care. 2013 March; 30(2): 121-127. doi:10.1177/1049909112445371.

On Sinking and Swimming: The Dialectic of Hope, Hopelessness, and Acceptance in Terminal Cancer

Emily Sachs, PhD¹, Elissa Kolva, MA¹, Hayley Pessin, PhD², Barry Rosenfeld, PhD¹, and William Breitbart, MD²

¹Psychology Department, Fordham University, Bronx, NY, USA

²Department of Psychiatry and Behavioral Medicine, Memorial Sloan-Kettering Cancer Center, New York, NY, USA

Abstract

For terminally ill cancer patients, hope and hopelessness are constructs that significantly impact the quality of life. The aim of this study was to examine the relationship between hope and hopelessness in advanced cancer and to identify factors that maintain hope and increase vulnerability to hopelessness. Semistructured interviews were conducted with 22 terminally ill cancer patients. Interview transcripts were analyzed using thematic content analysis to identify patient definitions of these terms and associated cognitions and emotions. Hope and hopelessness were identified as distinct, often co-occurring, and dialectically interacting constructs. The relationship between hope and hopelessness often balanced on acceptance, perceived as diametrically opposed to hopelessness, and conducive to redirecting hope toward new goals. Positive interpersonal relationships enhanced hope, and uncontrolled physical pain increased vulnerability to hopelessness.

Keywords

cancer; terminal	illness; hope;	hopelessness	acceptance; end	d of life	
	•	•	-		

Introduction

Patients diagnosed with terminal illness must cope with increasing physical limitations as well as the emotional impact of the illness and, in particular, the poor prognosis. In the context of these stressors, some patients appear to be overwhelmed by feelings of hopelessness or despair. Others focus on hope for a cure or long-term survival despite the contradictory evidence, while still others acknowledge a terminal prognosis but develop hope for more proximal positive or meaningful experiences. Thus, hope and hopelessness have been identified as significantly related to quality of life for patients with terminal

Reprints and permission: sagepub.com/journalsPermissions.nav

Corresponding Author: Emily Sachs, PhD, Psychology Department, Fordham University, 441 E Fordham Rd, Bronx, NY 10458, USA, esachs1@gmail.com.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

cancer.^{2,3} Hope is associated with greater psychological and spiritual well-being and the utilization of more effective coping strategies,⁴ while hopelessness is associated with poorer quality of life and increased incidence of psychopathology and desire for hastened death.²

Quantitative and qualitative studies have investigated the definitions, covariates, and roles of hope and hopelessness in terminal cancer, generally as 2 distinct constructs.^{3–6} Similarly, studies seeking to develop standardized measures of these constructs have mainly focused on either hope or hopelessness (ie, Beck Hopelessness Scale,⁷ Herth Hope Index,⁸ Hopelessness Assessment in Illness,⁹ and Miller Hope Scale¹⁰). Rarely has research addressed hope and hopelessness simultaneously to elucidate the relationship between these 2 constructs in the context of incurable illness.

Certain questions can only be answered by examining hope and hopelessness together. For example, is the nature of hopelessness simply the absence of hope, or is hopelessness a separate construct with distinct implications for quality of life in terminal illness? Can hope and hopelessness exist at the same time within a patient's experience, and if so, what is the relationship between the 2? For patients struggling to maintain hope, is hopelessness perceived as the only alternative? The present study uses the testimony of terminally ill cancer patients to address these questions. Themes relevant to the relationship between hope and hopelessness are identified, as well as factors that may facilitate the adaptive use of hope in coping with terminal illness, and factors that may increase vulnerability to hopelessness.

Hope

A clear and concise definition of hope in the terminally ill has yet to be fully articulated.³ Broad definitions describe hope as a positive orientation toward one's future.¹¹ Medical professionals typically define hope in terms of disease prognosis.¹¹ In the psychology literature, Gum and Snyder⁵ conceptualized hope as the ability to generate workable routes to desired goals in the face of a threat. Definitions of hope in the nursing literature tend to be multifactorial, encompassing affective, cognitive, personality, behavioral, relational, spiritual, and/or temporal dimensions.^{6,12} It is widely acknowledged that a terminal illness can shift an individual's priorities and goals. The notion of hope as a positive expectation for goal attainment is seriously challenged when one's primary goal of survival may no longer be possible. Therefore, some researchers have found that hope at the end of life often refers to new targets, such as hope for comfort, dignity, intimacy, or salvation.¹¹ Sullivan¹¹ suggested that the challenge at the end of life is not so much protecting or restoring hope, as it is diversifying and redirecting hope.

Hope as active coping—McClement and Chochinov³ defined hope in patients with advanced cancer as a coping mechanism, protecting patients from the experience of distress and suffering. In their theoretical discussion of the relationship between hope and hopelessness, Hammer and colleagues cited philosopher Gabriel Marcel's definition of hope: "Hope comes into being only when the possibility for despair gains access." ^{13(p274)} In a review of 26 quantitative research articles of hope in patients with cancer, Chi⁴ found a significant positive relationship between level of hope and effective coping styles (ie, active acceptance, engaging in normal living activities and reconciling with life and death) among

patients with cancer. Folkman¹⁴ also described a dynamic and reciprocal relationship between hope and coping in the context of stress and found that hope is essential for coping with the chronic stress of serious illness. Active coping can engender hope, and in turn hope can energize coping activities. Eliott and Olver¹⁵ found that hope helped dying cancer patients maintain a positive outlook, connect with others, and engage with life.

Hopelessness

Hopelessness initially emerged from the psychiatric literature as a symptom of depression. It has since been recognized as a distinct construct related to a host of negative outcomes at the end of life. 11 As with hope, the extant literature contains various conceptualizations of hopelessness. From a psychodynamic perspective, hopelessnes is defined as "an inability to retain a good object feeling and to generate self-soothing, self-affirming responses in the face of disappointment," which can lead to feelings of emptiness and despair. 16(p300) Cognitive theorists, led by Beck and colleagues, view hopelessness as the presence of negative expectations and a pessimistic attitude toward the future. Sullivan directly addressed hopelessness in the terminally ill as reciprocally linked to the patients' health state and suffering. Rather than being characterized by the absence of hope, Sullivan proposed that hopelessness is a maladaptive attachment to a form of hope that has been lost.

Hopelessness has been identified as an important construct in understanding desire for hastened death, suicidal ideation, and requests for assisted suicide in the terminally ill.² Although suicide is often linked to depression, several studies found hopelessness to be a stronger predictor of suicidal ideation than depression in patients with terminal illness.^{2,17–19}

Hope and Hopelessness

The relationship between hope and hopelessness has rarely been systematically examined in research, despite numerous studies describing these constructs individually. Past researchers have suggested that hope and hopelessness are anchors on a continuum. ^{20,21} McGee stated that hope and hopelessness are polar opposites and that "hopelessness represents the extreme state of despair in which all hope is lost." ^{21(p39)} In contrast, Kylma and colleagues²² provided one of the few investigations addressing both hope and hopelessness concurrently. In their qualitative study, patients living with AIDS and HIV defined hope as the belief that life is worth living at present and in the future. They identified an active component to hope, stressing that it facilitates coping with disease-related stressors. Hopelessness was identified as a more passive construct composed of affective (a lack of hope), cognitive (lack of future expectations), and motivational (giving up) components. This description of hopelessness is similar to the dimensions identified in the Beck Hopelessness Scale, ⁷ where hope and hopelessness are represented as 2 theoretically distinct but dialectically interacting constructs.

Our clinical experience with terminally ill cancer patients receiving state-of-the-art, integrated care at both inpatient and outpatient medical facilities in New York City has inspired extensive discussion about the relationship between hope and hopelessness in this vulnerable population. Our research and clinical staff have collaborated to develop a

measure of hopelessness specifically for patients with advanced cancer. The prior research literature alludes to a potential dynamic (as opposed to diametric) relationship between hope and hopelessness but does not investigate this relationship. The present study attempts to address this gap in the literature. This investigation is largely exploratory, with the goal of giving voice to our patients' subjective experiences of terminal illness, and their personal knowledge of the roles of hope and hopelessness in that experience. Based on our review of the literature, we approached the data with particular interest in the possible dialectic between hope and hopelessness, and the conceptualization of hope as an active coping strategy in the face of existential threat.

Methods

This study was approved by the Institutional Review Boards of Memorial Sloan-Kettering Cancer Center, Calvary Hospital and Fordham University. The data were collected in the course of a study that eventually led to the development of a measure of hopelessness for patients with advanced or terminal disease. Patients were 30 English-speaking adult patients with stage IV cancer (ie distant metastases) and a life expectancy of less than 1 year. Participants were recruited from 2 hospitals (15 from each site): a palliative care hospital for terminally ill cancer patients and a tertiary cancer care center. Life expectancy was determined through consultation with the referring physician; participants recruited from the palliative care hospital typically had a life expectancy of less than 6 weeks, whereas those recruited from the cancer center typically had a life expectancy of 3 to 12 months. Eligible patients were referred by their physicians to the investigators. All patients approached agreed to participate in the study. Prospective study participants were approached by study researchers either in their hospital room or while waiting for an outpatient medical appointment. Participants were informed of the nature of the study including potential risks and benefits, and informed consent was obtained.

Participants subsequently participated in 1 semistructured interview conducted by a clinical psychologist or psychology graduate student that was derived from interviews with leading scholars and researchers in the field of palliative care, oncology, and psychiatric functioning at the end of life (see Rosenfeld et al⁹). During interviews, participants responded to a focused set of open-ended target questions developed to meet the needs of the parent study (see Table 1). Participants were asked to rate their levels of hope and hopelessness. These ratings were then used to elicit descriptions of the cognitive and affective experience of these constructs and were not used in quantitative analyses. Participants were also asked about their health status along with their emotional, physical, and spiritual quality of life. Interviews were audio taped and transcribed by the research team, omitting all identifying information. The final data set includes participants' direct answers to research questions as well as comments and themes spontaneously generated by participants.

The data analysis team consisted of the study's principle investigators (ie, trained psychology graduate students). The interview data were reviewed and interpreted using thematic content analysis with an inductive, data-driven approach.^{23–26} First, a trained rater read all patient transcripts and identified salient points, themes, and ideas linked to strong emotional affect in patients' responses to the set of target questions. These passages were

then collapsed, in a second level of coding, into a number of different categories that reflected the various features of hope and hopelessness articulated by the study participants. All team members reviewed these passages to confirm the identification of content areas of interest given the research questions. Using inductive coding techniques, ^{27,28} passages that conveyed the participants' perceptions of and experience with hope and hopelessness were identified. Two raters (both psychology graduate students) conducted the first round of coding separately and met weekly to discuss and revise the code list, and select illustrative patient quotations. Both raters eventually coded the entire set of patient quotations, for interrater reliability, and ultimately produced a codebook consisting of 17 codes. Rigor in our qualitative analysis was derived from rounds of iterative consensus work among team members (ie, the 2 primary raters and a third clinical psychologist) who analyzed and reviewed transcripts, reconciled coding discrepancies, and agreed on code names and definitions.

Thirty patients consented to the study, and complete data were provided by 22 (73.3%) of the participants. Two participants were excluded because they failed to meet the eligibility criteria (no evidence of disease). The remaining 6 participants had cognitive limitations that precluded them from providing meaningful data for this analysis. Twelve of the participants (54.5%) were receiving inpatient palliative care and 10 (45.5%) were receiving outpatient care. The sample was mostly female, with 15 (68.2%) women and 7 (31.8%) men. The majority were caucasian (81.8%, n = 18), with 18.2% (n = 4) African American; 86.4% (n = 19) were non-Hispanic; and 13.6% (n = 3) Hispanic. Eight participants (36.4%) identified as Catholic, 7 (31.8%) as Jewish, 6 as other Christian faiths (27.2%), and 1 (4.5%) individual reported no religious affiliation. The average age was 58.5 (range: 30 to 80). All of the participants met criteria for advanced cancer (stage IV) and included a variety of primary diagnoses (lung: 13.6%, n = 3; pancreatic: 13.6%, n = 3; ovarian: 18.2%, n = 4; prostate: 9.1%, n = 2; breast: 13.6%, n = 3; and 18.1%, n = 4 had other cancer diagnoses). Two participants (9.1%) were still alive at the conclusion of the study.

Findings

Patient responses indicated that they experienced hope and hopelessness as closely linked constructs. For many participants, consideration of one construct led automatically to a discussion of the other. This provided support for the idea, articulated by Marcel¹³ that hope becomes relevant when the threat of despair or hopelessness is introduced. The analysis also yielded some unexpected findings. For example, it was apparent that patients' experience of hope and hopelessness frequently balanced on a third critical construct: acceptance. Finally, patient reports suggested several psychosocial factors that may enhance hope or increase vulnerability to hopelessness. These findings are described in more detail below.

Hopelessness as a Threatening Psychological State

When study participants were asked about experiences of feeling hopeless, many described a pervasive negative state that extends beyond a sense of loss or disappointment, into such territories as depression, despair, numbness, and even surrender. One patient observed, "Hopelessness I guess is where you are looking at it as though nothing will help, not internal

resources and not external resources, like shutting down all. There are no options." Another described feelings of hopelessness as all-encompassing:

Yeah, last week I got into hopelessness.... I wouldn't cry. I would do nothing. I wouldn't talk. I wouldn't eat.... I thought I would die by now, and because of that I gave over hope totally. I was just lying there waiting to die.

Many patients seemed to view even transient feelings of hopelessness as potentially dangerous or disabling, as if such feelings might trigger a cascade of functional decline and block emotional access to former sources of resilience. One patient's anxiety was palpable as she responded, "You know I just cannot be hopeless like, why bother to do anything? I have to work. If you're hopeless why bother to work? Why bother with anything?" Another considered, "Once you start feeling hopeless it's over... I can't imagine what that would be like. That would be bad, that would be bad." Consistent with this idea of hopelessness as a threatening state of mind, some patients reacted to being asked whether they had ever felt hopeless with expressions of anxiety, fear, or even anger. One patient objected that she "shouldn't even be forced to think about that."

Relationship Between Hope and Hopelessness

By asking study participants about both hope and hopelessness, it became clear that the constructs are closely linked in patients' minds. Participants often discussed hope when asked about hopelessness and vice versa. "Do I feel hopeless? I mean, sure. I feel hopeless and I feel hopeful. You know, I think one feels both at the same time."

Many patients described hope as a tool for fending off the threat of hopelessness: "You're just looking for some escape. It's fleeting, it's fleeting you know. If you go a whole lot into hopelessness, it'll kill you.... I am learning today of being hopeful and to smile." Some participants specifically described their relationship to hope as a sort of dialectic, battle, or balancing act:

I start thinking I have two choices, I can either sink or swim, and then I start telling myself about the different research that I have done on the internet, that there is always tomorrow and there could be a breakthrough and there could be a cure... It is just a reasoning with myself, but when I do get out of it – hopelessness - I do not understand how did I get there ...

Another patient observed:

It is like you get down there and, and you go like no, I cannot stay here, I cannot and it is like a war that is raging inside of you ... the hope for one minute and then the [doubts] all start off and you feel like you are deteriorating.

Thus, the conventional view of hopelessness as the absence or opposite of hope appears to miss the dialectic between the 2 constructs. Patients described employing hope as a coping tool to help move them away from threatening emotional states (such as hopelessness) that may arise in the context of terminal illness and toward more positive feelings, actions, and goals.

Acceptance

As patients discussed hope and hopelessness in relation to their advanced illness, acceptance emerged as an integrally related construct. There were no explicit questions about acceptance in the study interview script; rather, acceptance was spontaneously introduced by many patients in response to questions regarding their present levels of hope and hopelessness, and about specific things they were hoping for. One participant stated, "I accept what is. If I go, I go. If I live, if I can get around and do things again, that's the best thing I could ever look forward to."

Some participants who discussed acceptance also warned of potential negative consequences of false hope 16 or of inflexibly clinging to specific hopes at the expense of some sense of acceptance. As 1 patient explained,

I think there are so many ifs in this disease and so many things can go wrong ... so you cannot be too hopeful, you know, so you kind of have to be realistic.... If you are too hopeful, you might get disappointed, you know?

Acceptance thus implies a realistic understanding of prognosis and a willing relinquishing of inflexible or unrealistic hopes. Some patients further suggested that acceptance allowed them to enjoy other aspects of life, such as time with loved ones and nature and to use hope in a more adaptive way, that is, to hope for new or modified goals. One patient stated "I am hopeful for each day, you know. I mean I know I am not going to be cured, there is no cure, but I am hopeful that I have as wonderful a time as possible." Another stated:

I no longer assume that I will have a long life and that has taken a long time to get used to, but my expectations of the future have changed ... you know, I do not expect to grow old. I hope I grow old.

In other words, accepting the major changes that come with a diagnosis of a terminal illness can allow an individual to turn to appropriate coping strategies, including developing more realistic hopes for the future. Patients often discussed hope for intermediate goals (rather than long-term survival), for quality of life, for participating in important personal, family, or societal milestones, for creating a positive legacy, and even for the future success and happiness of loved ones after their own death.

In discussing acceptance, many participants brought up topics related to self-worth and completion of life goals. They seemed to suggest that fulfillment of life goals allows for acceptance of one's prognosis and thus the adoption of more realistic forms of hope, which in turn protects against hopelessness. One patient commented:

When you talk about hope and hopelessness, I feel that basically in my life, I mean there are a couple of things that I regret not doing but basically I have done what I wanted to do, you know and that's a good feeling, and it's a good feeling to know that people will remember me as being helpful and having contributed something. And that makes a difference than if I didn't feel that I lived my life the way I wanted to.

Given this framework for understanding the interdependent constructs of hope, hopelessness, and acceptance, we were able to identify some specific factors that may enhance acceptance and hope, and those that may increase vulnerability to hopelessness.

The Protective Role of Family Relationships

Family relationships appeared to play a strong role in some participants' ability to maintain hope, develop acceptance, and ward off hopelessness. Consistent with hope-maintaining factors identified by Chi,⁴ some patients spoke of the "cheerleading" of loved ones increasing their own sense of hope. For example,

My daughter's brainwashing that she tells me, there are ways, we are going to find them, we are not going to give up.... She is the one who builds me up. And my grandson who calls me all the time—"You've got to be strong, don't give up. Look at me. I didn't do well in biology and now I have the highest grade in the class. So don't give up." That's what I was thinking of [when I talked about hope].

Although some patients focused on hope for cure when it came to interacting with their children, others described the importance of family relationships in facilitating acceptance, thus allowing hope for more proximal events. "I think about my kids and my family, being with them, experiencing things with them, and being there for them."

Some participants felt an obligation to remain hopeful for the sake of others. This introduces the possibility of "public" versus "private" hopes that may not be entirely compatible, as for one participant who emphasized the need to hide more complex feelings from friends and family:

In the back of my mind, I am always not completely hopeful. I don't really think that I can make it ... if I'm honest with myself. Yeah, but at the same time, I am telling everyone else that I am completely hopeful.

Although expressions of hope from family members may help patients maintain their own hope, these interviews suggest that the desire to take care of loved ones may undermine a patient's own need for greater acceptance of their situation, and thus their ability to identify realistic new targets of hope.

Role of Physical Pain and Major Depression

Several participants reported that poorly controlled physical pain or disability, rather than a reaction to their diagnosis, was the cause of their hopelessness. When pain management was improved, in some cases after a transfer into hospice care, these patients reported reduced hopelessness and the return of feelings of hope. One patient stated, "this morning, I wake up and I don't have pain, nausea… I am so happy. I said instead of, '[God] why don't you hear me,' 'Thank you for giving me another day."

In most cases, resolution of acute pain was accompanied by an increase in both hope and acceptance. One patient recalled a hospital stay during which she lost the use of her legs and her pain was poorly controlled: "When I realized I can't use my body anymore, I can't drive a car, I can't help people, I said my life is over for good. I was devastated. You know, you want to die." However, she experienced a dramatic shift in her mood and attitude after she

was transferred into hospice care, where she received pain management and social work services:

I have such angels working around me. When I said to them 'How long can I stay?' and they said 'As long as you want,' I mean there's just a feather in my cap. My whole attitude is different.... I accept what it is. If I die, I know I will die in peace. Whereas before I was in physical pain and I was mentally in pain because I felt so useless.

A similar phenomenon was described with the psychological pain of major depressive disorder. Two participants discussed precancer episodes of severe depression, during which hopelessness was a dominant symptom. They spoke of advanced cancer as relatively manageable compared to their depressive episodes and, subsequent to effective depression treatments, demonstrated notable resilience to hopelessness at the end of life.

I inherited [depression] from my father who committed suicide, but I have not had an attack in a long time ... those were terrible—it is the worst possible type of illness to have a black depression. For that even death or cancer does not bring it on.

Another patient described:

I was very despondent and felt totally depressed, I couldn't see any way that I could, you know, live a happy life at all ... It was even worse than having cancer ... really I felt so hopeless because I didn't know what to do,... I just am so grateful that they have these new medicines for depression because without that, I think people would be in bad shape, I know I would have.

Discussion

Semistructured interviews with patients with advanced cancer, conducted by mental health professionals with extensive experience working in psycho-oncology and palliative care settings, provided a unique opportunity to explore the inter-relationships between hope and hopelessness in terminal illness. Prior theoretical papers and research studies have primarily addressed hope and hopelessness separately. This study reflects one of the first attempts to systematically explore the relationships between these constructs, using interviews with advanced cancer patients as the data source. A significant limitation of this study is that it was not designed as an independent qualitative study; rather, the data were collected in the exploratory phase of a quantitative study to develop a measure of hopelessness, and the present findings are the result of secondary analysis. Thanks to this exploratory research, we observed that patients routinely discuss hope when asked about hopelessness and vice versa and pursued a deeper review of their narratives to elucidate the relationship between hope and hopelessness.

Study participants described hope as an active means of protecting against existential threat (ie, hopelessness). Rather than an end point on a continuum, hope seems to play a dynamic role in patient experience, functioning primarily as a coping mechanism. This conclusion is consistent with Chi's⁴ definition of hope as an active strategy that is positively related to the

use of other coping behaviors. Furthermore, the foci of participants' hopes were diverse and included both long-term and short-term objectives. These findings support Folkman's ¹⁴ conceptualization of hope as an essential for coping with prolonged stressors.

In contrast to hope, study participants characterized hopelessness as a diffuse, persistent, dark state, which can threaten one's ability to cope or function effectively in various domains. Consistent with Beck et al⁷ and Kylma et al's²² conceptualizations, discussions of hopelessness resulted in strong affect-laden responses alluding to the overwhelming nature of this state. Hope and hopelessness thus appear dialectically related to one another, where hope arises as an adaptive mechanism for coping with the threat of a feared state like hopelessness (consistent with Hammer¹³); and hopelessness seemed to take root at times of frustrated attachment to forms of hope that have been lost. ¹¹ This conceptualization of hope and hopelessness as interdependent constructs is supported by participant accounts of experiencing both at the same time.

An unexpected finding from this study was the emergence of acceptance (rather than hope) as opposite to hopelessness. Acceptance of one's terminal prognosis was related to more adaptive forms of hope, such as hope for connection with others, enjoyment of daily pleasures, and investment in legacy projects, rather than hope for extended life. In other words, through acceptance, patients appeared better able to utilize hope as an effective coping mechanism, warding off morbid states such as hopelessness. Our findings of this mutually supportive relationship of hope and acceptance is also consistent with Chi's⁴ findings that patients with high levels of coping engaged in active acceptance, activities that delivered a sense of normalcy and reconciling with life and death.

Finally, this study identified several factors that may facilitate the use of hope and acceptance or increase one's vulnerability to hopelessness. Several participants clearly articulated that poorly managed pain or severe physical disability were the cause of feelings of hopelessness. These patients described that the introduction of adequate palliative care dissipated hopelessness, and in some cases resulted in new feelings of acceptance and hope for realistic goals. This finding is largely unsurprising as uncontrolled pain is strongly associated in prior research with depression, hopelessness, and desire for hastened death. ²⁹ Ironically, 2 participants believed that their history of severe depression was a protective factor against hopelessness as they struggled with terminal cancer. Essentially, overcoming mental illness through psychiatric treatment increased these patients' resilience and allowed them to more fully appreciate the pleasures and rewards of daily life while acknowledging its impermanence.

A second important factor identified by these patients was personal relationships, which appeared to increase their capacity for positive coping. In some cases, interpersonal relationships were protective, allowing patients who were employing both acceptance and hope to identify achievable goals. This is consistent with the findings in the literature on the protective effects of social support in patients with cancer. 30,31 Conversely, others identified pressure to appear constantly hopeful for their family members as an obstacle to processing their new reality and developing a sense of acceptance. Thus, the role of relationships in facilitating the use of hope as a coping mechanism, or increasing vulnerability to

hopelessness, is an important area for assessment as well as intervention. Family-based interventions that aim to foster appropriate hope in the face of terminal illness may be improved by targeting family interactions that promote public or false hope.

These findings also have implications for the measurement of hope, hopelessness, and acceptance. Quantitative research utilizing measures of hope, hopelessness, and acceptance within a single sample would be helpful to validate our findings. Additionally, the inclusion of all 3 constructs into a unified measure may allow for a more comprehensive study of the experiences of terminally ill cancer patients, and particularly the relationships between hope, hopelessness, and acceptance and other aspects of psychological distress (ie, depression, anxiety, desire for hastened death, low social support). At present, no such measure exists. These findings may also be helpful in informing clinician interactions with terminally ill cancer patients. Knowledge of the dynamic relationship between hope, hopelessness, and acceptance may aid clinicians in discussing these topics with their patients. Exploring hopelessness may be useful in identifying hidden emotions, addressing denial and unrealistic hopes, and in turn fostering more realistic objects of hope in patients. Treatments including acceptance, mindfulness, and dialectic approaches, such as Acceptance and Commitment Therapy³² or Dialectical Behavioral Therapy,³³ may be useful in increasing cognitive flexibility and redefining sources of hope. Furthermore, the role of family members in either maintaining hope or impeding acceptance and adaptation of hopes is an important area for intervention. Finally, these findings highlight the importance of optimal palliative care, as controlling pain, maximizing functioning, and treating psychopathology (eg, major depression) may be as critical to maintaining hope and warding off hopelessness as disease prognosis itself.

Acknowledgments

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

References

- 1. Miovic M, Block S. Psychiatric disorders in advanced cancer. Cancer. 2007; 110(8):1665–1676. [PubMed: 17847017]
- 2. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. JAMA. 2000; 284(22):2907–2911. [PubMed: 11147988]
- 3. McClement SE, Chochinov HM. Hope in advanced cancer patients. Eur J Cancer. 2008; 44(8): 1169–1174. [PubMed: 18359220]
- 4. Chi GC. The role of hope in patients with cancer. Oncol Nurs Forum. 2007; 34(2):415–424. [PubMed: 17573305]
- 5. Gum A, Snyder CR. Coping with terminal illness: the role of hopeful thinking. J Palliat Med. 2002; 5(6):883–894. [PubMed: 12685535]
- 6. Johnson S. Hope in terminal illness: an evolutionary concept analysis. Int J Palliat Nurs. 2007; 13(9):451–459. [PubMed: 18026064]
- 7. Beck AT, Weissman A, Lester D, Trexler L. The measurement of pessimism: the hopelessness scale. J Consult Clin Psychol. 1974; 42(6):861–865. [PubMed: 4436473]
- 8. Herth K. Fostering hope in terminally-ill people. J Adv Nurs. 1990; 15:1250–1259. [PubMed: 2269747]

 Rosenfeld B, Pessin H, Lewis C, et al. Assessing hopelessness in terminally ill cancer patients: Development of the Hopelessness in Illness Questionnaire (HAI). Psychol Assess. 2011; 23(2):325–336. [PubMed: 21443366]

- 10. Miller JF, Powers MJ. Development of an instrument to measure hope. Nurs Res. 1988; 37(1):6–10. [PubMed: 3340583]
- 11. Sullivan MD. Hope and hopelessness at the end of life. Am J Geriatr Psychiatry. 2003; 11(4):393–405. [PubMed: 12837668]
- 12. Dufault K, Martocchio BC. Hope: its spheres and dimensions. Nurs Clin North Am. 1985; 20(2): 379–391. [PubMed: 3846980]
- Hammer K, Mogensen O, Hall EO. Hope as experienced in women newly diagnosed with gynaecological cancer. Eur J Oncol Nurs. 2009; 13(4):274–279. [PubMed: 19282239]
- 14. Folkman S. Stress, coping, and hope. Psychooncology. 2010; 19(9):901-908. [PubMed: 20799373]
- 15. Eliott JA, Olver IN. Hope and hoping in the talk of dying cancer patients. Soc Sci Med. 2007; 64(1):138–149. [PubMed: 17011094]
- Levine R. Treating idealized hope and hopelessness. Int J Group Psychother. 2007; 57(3):297–317.
 [PubMed: 17661545]
- 17. Chochinov HM, Wilson KG, Enns M, Lander S. Depression, hopelessness, and suicidal ideation in the terminally ill. Psychosomatics. 1998; 39(4):366–370. [PubMed: 9691706]
- 18. Grewal PK, Porter JE. Hope theory: a framework for understanding suicidal action. Death Stud. 2007; 31(2):131–154. [PubMed: 17410693]
- 19. Rodin G, Zimmermann C, Rydall A, et al. The desire for hastened death in patients with metastatic cancer. J Pain Symptom Manage. 2007; 33(6):661–675. [PubMed: 17531909]
- Lang, SP. Hope. In: Carlsson, B.; Blackwell, B., editors. Behavioral Concepts and Nursing Intervention. Philadelphia, PA: JB Lippincott; 1978. p. 171-189.
- 21. McGee RF. Hope: a factor influencing crisis resolution. Adv Nurs Sci. 1984; 6(4):34–43.
- 22. Kylma J, Vehviläinen-Julkunen K, Lähdevirta J. Hope, despair and hopelessness in living with HIV/AIDS: a grounded theory study. J Adv Nurs. 2001; 33(6):764–775. [PubMed: 11298214]
- 23. Creswell, J., editor. Qualitative Inquiry and Research Design; Choosing Among Five Traditions. Thousand Oaks, CA: Sage Publications; 1998.
- Patton, MQ., editor. Qualitative Research & Evaluation Methods. 3rd. Thousand Oaks, CA: Sage Publications; 2002.
- 25. Green, J.; Thorogood, N., editors. Qualitative Methods for Health Research. London: Sage; 2004.
- Bernard, HR., editor. Research Methods in Anthropology: Qualitative and Quantitative Approaches. 2nd. Walnut Creek, CA: AltaMira; 1994.
- 27. Strauss, A., editor. Qualitative Analysis for Social Scientists. Cambridge, England: Cambridge University Press; 1987.
- 28. Strauss, AL.; Corbin, J., editors. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Thousand Oaks, CA: Sage; 1990.
- 29. Mystakidou K, Tsilika E, Pathiaki M, Patiraki E, Galanos A, Hlahos L. Exploring the relationships between depression, hopelessness, cognitive status, pain, and spirituality in patients with advanced cancer. Arch Psychiatr Nurs. 2007; 21(3):150–161. [PubMed: 17556108]
- 30. Bloom JR, Spiegel D. The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. Soc Sci Med. 1984; 19(8):831–837. [PubMed: 6505749]
- 31. Helgeson VS, Cohen S. Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. Health Psychol. 1996; 15(2):135–148. [PubMed: 8681922]
- 32. Hayes, SC.; Strosahl, KD.; Wilson, KG., editors. Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change. New York, NY: Guilford Press; 2003.
- 33. Linehan, MM., editor. Cognitive-Behavioral Treatment of Borderline Personality Disorder. New York, NY: Guilford Press; 1993.

Table 1

Interview Questions

•	On a scale from 0 to 10, 0 being <i>not hopeless at all</i> and 10 being <i>completely hopeless</i> , how hopeless do you feel right now?
•	What were you thinking about when you came up with that number? What came to mind?
•	On a scale from 0 to 10, 0 having <i>no hope at all</i> and 10 being <i>completely filled with hope</i> , how hopeful do you feel right now?
•	What were you thinking about when you came up with that number? What came to mind?
•	Have there been times more recently or in the past where you felt extremely hopeless? What was that like?
•	What were your thoughts and feelings at the time? How long did it last? Did it come and go or did you feel that way all the time?
•	What changed to make you feel more hopeful or less hopeless?
•	At this point, are there specific things you are feeling very hopeful about?
•	Are there specific things you are feeling particularly hopeless about or given up hoping for? Which of these is the most distressing or most important to you?
•	Do you have specific plans or goals that you want to accomplish?
•	How has your illness changed your goals and plans for the future?

What are the things that concern or worry you the most about the future?