

# Exploring Hope and Healing in Patients Living With Advanced Non-Small Cell Lung Cancer

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**L**ung cancer is the second most commonly diagnosed cancer in Canada (Canadian Cancer Society [CCS], 2012). An estimated 85%–90% of lung cancers are classified as non-small cell lung cancer (NSCLC), with almost half of patients with NSCLC presenting with advanced disease at the time of diagnosis (CCS, 2012). Advanced disease refers to NSCLC that has spread locally (stage IIIB) or distally (stage IV) to the lymph nodes or other tissues and organs (CCS, 2012). The five-year survival rates are poor at 13% and 19% for men and women, respectively (CCS, 2012).

Unsurprisingly, 43%–50% of patients with lung cancer experience psychological distress, surpassing the rates associated with all other diagnoses (Cooley, Short, & Moriarty, 2003; Tishelman et al., 2005; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). That distress has been linked to a number of cancer- and treatment-related factors that have been found to negatively affect the patients' social, physical, and spiritual well-being and quality of life (Akin, Can, Aydinler, Ozdilli, & Durna, 2010; Fan, Filipczak, & Chow, 2007; Thompson, Solà, & Subirana, 2005). Such distress also has been associated with poor adherence to treatment and low satisfaction with care, contributing further to poor health and survival outcomes (Graves et al., 2007; Kaasa, Mastekaasa, & Lund, 1989; Kukull, McCorkle, & Driever, 1986).

Although the terms are sometimes used interchangeably and their definitions overlap, distress is not a synonym of suffering but rather one of its components. Psychological distress is a predictor of suffering in patients with cancer (Wilson et al., 2007). Suffering has also been reported at all phases of the cancer trajectory and significantly affects patients' ability to cope with advanced disease (Chio et al., 2006; Ferrell & Coyle, 2008). One of the first to explore the affective experience of suffering, Cassel (1982) deplored the separation of mind and body, which he felt contributed to suffering being given scant attention as it was unjustly relegated

**Purpose/Objectives:** To explore the experience and meaning of hope in relation to the healing process of patients living with stage IIIB or IV non-small cell lung cancer.

**Research Approach:** Interpretative qualitative study design.

**Setting:** Peter Brojde Lung Cancer Centre in the Jewish General Hospital in Montreal, Quebec, Canada.

**Participants:** 12 English- and French-speaking patients, aged 36–78 years.

**Methodologic Approach:** One 60–90-minute semistructured interview per participant was conducted. An inductive approach to data analysis was taken, involving immersion in the data, coding, classifying, and creating linkages.

**Findings:** Four main themes emerged: (a) the morass of shattered hope, (b) tentative steps toward a new hope paradigm, (c) reframing hope within the context of a life-threatening illness, and (d) strengthening the link between hope and wellness.

**Conclusions:** Patients described a process where hope was diminished or lost entirely, regained, and reshaped as they learned to live and grow following their diagnosis.

**Interpretation:** This study adds to the literature by describing the dynamic nature of hope as well as factors facilitating or hindering the hope process. It demonstrates how finding meaning, a structural component of healing, can be used to envision a new hopeful future. This study suggests hope and healing cannot exist in isolation, and highlights the importance of understanding the fluctuating nature of hope in patients with advanced lung cancer to foster it, therefore promoting healing.

**Key Words:** hope; healing; meaning

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to the realm of the mind, thereby giving it less credibility within medicine. Cassel (1982) posited that suffering is experienced by the whole person and occurs when the “impending destruction of the person is perceived” and lasts until the threat has passed or until the person can restore a new sense of integrity (p. 640). This suffering occurs in any of the multiple facets of the person (e.g., physical, emotional, social, spiritual) (Cassel,

1982). Cassel's (1982) concept that suffering is linked to a crisis of meaning has been echoed throughout the literature (Dobkin, 2009; Egnew, 2005, 2009). The crisis of meaning is linked to the loss of one's previously known life, leading to a loss of perceived wholeness. Because suffering encompasses the many realms of personhood, it permeates the existence of the sufferer and is indicative of a need to heal.

Similarly, healing has been sidelined from the medical care narrative while science and curing have taken center stage. As more holistic understandings of health are brought back into the healthcare vernacular, more attention is paid to healing. Although the descriptions of healing vary, recurring themes include wholeness and finding meaning (Dobkin, 2009; Egnew, 2005; Erickson, 2006). More specifically, the "existential plight" of cancer has been attributed to a loss of meaning following a cancer diagnosis (Lee, 2008). The healing process has been described as the process of achieving integrity and wholeness through acceptance of the self and of one's current situation (Mount, Boston, & Cohen, 2007). Finding new meaning within a life with cancer, defined as having a sense of order and purpose in life, allows patients to engage actively in life despite the many changes brought on by diagnosis (Lee, 2008). Through acceptance of the present situation, individuals can be whole within a new paradigm rather than clinging to a past version of themselves (Mount et al., 2007). These views on healing are captured succinctly by McElligott's (2010) operational definition of healing as "the personal experience of transcending suffering and transforming to wholeness" (p. 251). Although the process of healing has been described from various perspectives, the catalysts and mechanisms through which healing may be facilitated—specifically in patients with lung cancer—have yet to be elucidated (Erickson, 2006; Koithan et al., 2007; Mulkins & Verhoef, 2004).

## The Concept of Hope and Its Relation to Healing

Hope in patients living with a life-threatening illness is associated with health and well-being (Herth, 1990; Johnson, 2007). Feelings of well-being arguably reflect a sense of wholeness, so hope may function as a potential mediator of the healing process (Magaletta & Oliver, 1999). Reviews of qualitative studies provide examples of attributes of hope and what hope looks like to individuals living with a life-threatening diagnosis, as well as some suggestions on how to foster hope in individuals living with a life-threatening illness (Buckley & Herth, 2004; Herth, 1990; Johnson, 2007; McClement & Chochinov, 2008; Post-White et al., 1996). However, a clear operational definition of hope and the mechanisms by which it may be associated with healing are still lacking.

A few tools (e.g., Herth Hope Index, the Hope Index, the Stoner Hope Scale) have been developed to try to capture hope in a quantitative way (Herth, 1992; Schrank, Stanghellini, & Slade, 2008). Some of these tools include items such as social support and spirituality as apparent attributes of hope, whereas concepts of spirituality and social support, in particular, tend to be treated in the literature more as concepts in their own right (Herth, 1990; Schrank et al., 2008). That lack of conceptual clarity led the authors to develop a qualitative study of hope in relation to healing.

Findings from studies that have explored the evolution of hope throughout an illness narrative suggest that hope may be present at all stages of living with a life-threatening illness, although it may mean different things at the various phases of each illness (Herth, 1990; McClement & Chochinov, 2008). In addition, Herth (1990) has reported that diagnosis is the only demographic factor to have a significant effect on hope, suggesting that some diagnoses may have a more negative impact on hope than others. Therefore, certain populations, such as highly distressed patients with advanced lung cancer, may be particularly at risk for experiencing low levels of hope or hopelessness (Zabora et al., 2001).

A qualitative study by Reb (2007) sought to describe the experience of hope in women with advanced ovarian cancer. Hope did not emerge as the patients' main concern, but it was closely linked to the study's core variable, "transforming the death sentence." Reb (2007) described the experiential process of healing in terms of shock (i.e., reverberating from the impact), aftershock (i.e., grasping reality), and rebuilding (i.e., living the new paradigm). Although levels of hope may fluctuate throughout the illness experience, the relationship between hope and patients' innate healing processes has not been specifically described.

In addition, no study has explored hope in terms of the desired outcomes of healing: a sense of renewed acceptance, wholeness, or meaning in one's life (Erickson, 2006). Feldman and Snyder (2005) proposed that hope is a component of life meaning, with meaning being a larger concept than hope. Meaning is an outcome of healing, which suggests that Feldman and Snyder (2005) considered hope to be a component within healing. The current study's authors felt it necessary to further explore the relationship between hope and healing, particularly because hope and the process by which it is restored have not been the focus of studies involving highly distressed patients with advanced lung cancer.

Although a wealth of knowledge exists with regard to the healing process and the role of hope in health and illness, the relationship between these concepts has yet to be clarified. Guided by the concepts of hope and healing, the purpose of this qualitative study was

to explore the experience and meaning of hope and its potential relation to healing in patients living with advanced lung cancer.

## Methods

### Design

The authors used an interpretative, qualitative study with semistructured interviews to gain a better understanding of the experiences and beliefs about hope in relation to the process of emotional healing following a life-threatening diagnosis (Heidegger, 1962; Thorne, Kirkham, & Macdonald-Emes, 1997). That design is ideal when studying complex phenomena because it helps to identify themes and patterns while providing rich data on the subjective human experience (Maxwell, 1992).

### Setting and Sample

The Peter Brojde Lung Cancer Center (PBLCC), part of the Jewish General Hospital (JGH) in Montreal, is a referral center for patients with lung cancer in the province of Quebec. The PBLCC uses a model of integrative oncology practice based on important contributions from the disciplines of nursing, integrative medicine, and traditional Chinese medicine (Grossman, Agulnick, & Batista, 2012).

Purposive sampling was used to deliberately choose participants with characteristics that best contributed to the study objectives according to the following inclusion criteria: (a) a diagnosis of advanced NSCLC defined as stage IIIB and IV, (b) capable of conversing and reading in English or French, (c) older than age 18 years, and (d) followed at the clinic on an outpatient basis. Maximum variation in age, gender, language, education, marital status, and past experiences with cancer was sought during recruitment. Exclusion criteria included participants whose functional status did not allow them to travel to or participate in an interview while at the PBLCC.

### Data Collection

Recruitment and data collection occurred from September to December 2012 at PBLCC. According to Guest, Bunce, and Johnson (2006), a sample size of 12 tends to generate 92% of the codes produced by a total sample size of 30. The sample size was based on the saturation principle, whereby data collection continued until no new information was provided.

The nurse clinician, who closely follows patients with lung cancer in the clinic, screened patients according to the inclusion and exclusion criteria. If patients were interested in learning about the study, the researchers introduced themselves and described the study's goals and methods. The researchers obtained informed and

written consent from all interested participants, and an appointment for the interview was made at the participant's convenience.

Data collection consisted of a single 60–90-minute, semistructured interview conducted in French or English in a private room at the PBLCC. The discussion was guided by six broad questions, which were aimed at exploring the concept of hope in relation to the healing process (see Figure 1). During the interview, additional probing questions were used to clarify patient remarks and obtain deeper explanations. A previous study at the center revealed that use of the term *healing* was not well understood by patients (Amichai, Grossman, & Richard, 2012). As a result, the current interview guide used questions focusing on the known elements of the healing process—such as changes in thoughts, feelings, and beliefs at diagnosis as well as during and after treatment completion—to elicit the

**Preamble:** This study is designed to further understand your experiences and beliefs about the process of restoring a sense of well-being in your life. This interview should last no longer than an hour and a half, and there is the possibility of a follow-up phone call lasting no longer than 15 minutes if we discover a topic that requires clarification. Thank you for agreeing to participate.

#### How are you doing now?

#### Would you like to take me back to when you were first diagnosed? What happened?

- What were you thinking at the time of your diagnosis?
- How did it make you feel?
- What were your beliefs surrounding this diagnosis?
- What was hope like for you at that time?

#### Given where you are now, what has the process been like of going from that diagnosis to now?

- What has been helpful for you?
- What has not?

#### Would you tell me more about whether or not hope has been a part of this process?

- What is hope like for you now that you have had some time since the diagnosis?

#### Do you feel that you have changed in any way in terms of your approach to things? If so, would you please describe these changes?

- What about changes in the way you think?
- Any changes in the way you feel?
- Would you describe how your beliefs have changes? If at all.
- In what way do you think your relationships with others have or have not changed?

#### What does hope mean to you?

- Tell me about your hope. What kinds of things do you hope for?
- What things cause you to lose hope?
- What helps you to maintain your hope or makes you feel hopeful?

*Note.* Bullet points refer to prompts to gather more information where appropriate.

### Figure 1. Semistructured Interview Guide

presence of healing processes in patients. Participants also completed a sociodemographic questionnaire.

All interviews were audio recorded, transcribed verbatim within 24 hours, and completed by field notes about the environmental characteristics of the interview, as well as the patients' non-verbal communications. The interviews conducted in French were first transcribed verbatim to serve as a reference before being translated into English. The French interview and translation were conducted by one of the researchers, who is a native speaker of both French and English and can therefore capture the subtleties expressed in both languages.

The researchers held three training sessions to practice the interview process and test the interview guide. During these sessions, themes were independently generated and then collaboratively compared, discussed, and adjusted as necessary (Burnard, 1991), allowing the researchers to assess and enhance the consistency in their interview approach.

Data Analysis

The analysis followed an inductive approach, defined as the process of reasoning from specific observations to more general rules. It involved data immersion, coding, classifying, and creating linkages (Burnard, 1991; Polit & Beck, 2008). The researchers read and reread the transcripts so that the study participants' experiences would be fully understood (Burnard, 1991). Coding involved rereading transcripts and highlighting significant statements related to the healing process and its relationship to hope. Coded concepts were mapped onto a matrix by classifying data and formulating meanings and links between codes, allowing the extracted meanings to be further linked by grouping meanings into categories and then themes. Themes were compared across the participant sample using a cross-comparison analysis of the matrix.

Researchers independently generated themes that were collaboratively compared, discussed, and adjusted as necessary. Themes and preliminary results were further refined and verified by returning to the original transcripts, by peer review, and by discussing and corroborating with project supervisors (Burnard, 1991).

Data Trustworthiness

Trustworthiness, defined as the degree of confidence the researchers have in their qualitative data, was enhanced by ensuring study credibility, confirmability, dependability, and transferability were maximized (Polit & Beck, 2008). Peer debriefing by the researchers with each other, the senior researcher, and other members of the research team enhanced trustworthiness at all stages of data collection, coding, and analysis. The study was approved by the scientific review committee

of the McGill Ingram School of Nursing and the JGH Ethics Committee.

Results

Participants

A diverse sample of 12 participants living with NSCLC was recruited (see Table 1). Most participants currently had a partner and some past experience with cancer via relatives or close friends with the disease. All patients received treatment on an outpatient basis.

The participant narratives provided new insight into hope and the healing process. Data saturation was reached by the last interview, indicating that the framework captured the essence of the patient narratives. Patients described a process where hope was diminished or lost entirely, and regained and reshaped as

Table 1. Sample Characteristics (N = 12)

| Characteristic                          | $\bar{X}$ | Range |
|---|-----------|-------|
| Age (years)                             | 59.7      | 36–78 |
| Characteristic                          | n         |       |
| Age (years)                             |           |       |
| Younger than 40                         | 2         |       |
| 40–50                                   | –         |       |
| 51–60                                   | 4         |       |
| 61–70                                   | 4         |       |
| 71–80                                   | 2         |       |
| Gender                                  |           |       |
| Male                                    | 6         |       |
| Female                                  | 6         |       |
| Marital status                          |           |       |
| Married or common law                   | 7         |       |
| Widowed                                 | 1         |       |
| Separated or divorced                   | 2         |       |
| Single or never married                 | 2         |       |
| Education                               |           |       |
| High school                             | 5         |       |
| Vocational or technical college         | 4         |       |
| Bachelor's degree                       | 1         |       |
| Graduate degree                         | 2         |       |
| Origin                                  |           |       |
| Canada                                  | 8         |       |
| Europe                                  | 2         |       |
| South America                           | 2         |       |
| Native language                         |           |       |
| English                                 | 5         |       |
| French                                  | 5         |       |
| Spanish                                 | 1         |       |
| Greek                                   | 1         |       |
| Past cancer diagnosis in social network |           |       |
| Yes                                     | 7         |       |
| No                                      | 5         |       |
| Time from diagnosis                     |           |       |
| Less than 4 months                      | 5         |       |
| 4 to less than 8 months                 | 2         |       |
| 8 to less than 12 months                | 2         |       |
| More than 1 year                        | 3         |       |

they learned to live and grow in a dynamic new world following their diagnosis. That process was best understood by following the evolution of hope and healing in conjunction with their cancer trajectory. Each participant drew on processes of hoping and healing from their unique past experiences with health and illness. However, a number of similarities can be highlighted across participants. The process of restoring hope and healing seemed to be captured by four main themes: (a) the morass of shattered hope, (b) tentative steps toward a new hope paradigm, (c) reframing hope within the context of a life-threatening illness, and (d) strengthening the link between hope and wellness.

### **Morass of Shattered Hope**

Participants described the shattering nature of an advanced lung cancer diagnosis. Diagnosis and the time immediately following it were described as a period devoid of hope. Many depicted the initial difficulty of responding constructively to their diagnosis, describing the overwhelming uncertainty and crippling emotional distress that plagued them in this traumatic phase of the healing trajectory. This phase was most aptly described by three categories: (a) overwhelming losses, (b) emotional paralysis, and (c) challenges to rebuilding hope.

Participants reported an overwhelming sense of loss of their former concept of self. In addition, many participants reported a devastating loss of hope for the future, as one eloquently explained: "There is no more space for dreams. That's what I was thinking the other day. [That's] what allows us to go on sometimes in life even if you have reached a certain age . . . we dream." The loss of coping mechanisms used in the past was also described by another participant, saying, "As I am an anxious person, I always had to project myself in a better future. In the moment, I was never at ease internally . . . I was never well. Well, now I can't project myself anymore."

All participants reported being shocked by the diagnosis; many describing crippling emotional reactions as well as the overwhelming uncertainty associated with living with advanced lung cancer. One participant noted,

I realized [that] all my life I have had the capacity to choose what I needed to do. And now I can't decide anymore. I'm not guiding anymore. So, the fact that the cancer forced me to not be in the driver's seat anymore really disoriented me.

The emotional paralysis was characterized by disbelief and denial, particularly for those who did not smoke. "I felt great. I kept saying, 'Oh, well, maybe it isn't really lung cancer. Maybe it's a virus, and they'll give me an antibiotic, and I'll be on my way,'" remembered one participant.

Patients described factors that seemed to worsen their emotional paralysis and sense of loss in this initial phase, creating challenges to rebuild hope. Individuals stated that the diagnosis forced them to confront their perceived impending death, with one participant saying, "This question of mortality comes in every second." Facing their mortality and the poor prognosis associated with lung cancer were two of the many hope-harming elements. According to one patient, "When they say, 'Well, you gotta hope.' Yeah, but just how much knowing the odds. Always knowing the odds." Some reported the additional suffering associated with being given an estimated life expectancy by their healthcare provider. One participant said, "I was never really happy with what I've done with my life, for starters. And [the prognosis] set a deadline that I wasn't going to be able to meet."

### **Tentative Steps Toward a New Paradigm of Hope**

Whereas the diagnosis and the time immediately following were generally described as hopeless by most participants, the foundations for a hope-embedded future were set in this next phase. Patients seemed to oscillate between hoping for a return to their past healthy life and finding new reasons to hope for the future. Three subthemes emerged in this phase: (a) falling back on old ways of hoping, (b) out of the morass and onward, and (c) finding reasons to hope.

Patients still hoped to return to their past healthy lives, with one stating, "When somebody is sick, the best thing for [them] is to get better. There is nothing else in between. To get better. With health." Another described his experiences by saying, "I hope I can take that pill until my cancer is completely gone and I get to keep my lung . . . so that's my stupid hope." The hope reported at this time was steeped in the past as patients clung to a lost healthy self.

Despite hoping to return to their life prediagnosis, individuals reported reaching a point of exhaustion. As one participant reflected, "Eventually you get tired of all the questions and [the] worrying, and you realize that dying is going to happen to everyone."

After acknowledging the emotional exhaustion and lack of relief caused by overanalyzing their diagnosis, most reported a conscious effort to break the emotional paralysis by just "doing something" (i.e., out of the morass and onward). Many described the next step as action-based. As one individual stated, "It was not super important for me to be hopeful or to pray or whatever. It was more important to get [things] done. . . . I was more focused on action than hope, I guess." Patients seemed to take their first tentative steps away from emotional paralysis by applying proven strategies of imposing order and purpose to their new life experiences through

the lens of a life-threatening illness. This action-based approach helped patients emerge from their nebulous world bereft of hope.

Participants appeared to discover reasons to hope that helped them regain an ability to look forward as opposed to remaining trapped between a destroyed past and an uncertain future. One factor that served as a critical change agent was professionally facilitated hope, as one participant described: "He was really honest with me. He said, 'It is stage IV. It is considered that it cannot be cured, but its case by case because there are things we do not understand.'" The fact that medical advances have defied expectations and provided hope-inspiring stories seemed to have an ongoing and continuously positive effect on hope-rebuilding processes.

There was one guy who had survived that type of tumor for five years that my husband met. . . . I guess [the cancer] had recurred in some sort of way, and he was going back for more [chemotherapy], but he had survived for five years. So you cling to those things, however small.

As patients moved away from a focus on the past and found new reasons to hope, they appeared to be setting the foundation for constructing a new paradigm of hope and of the self in relation to healing.

### **Reframing Hope Within the Context of a Life-Threatening Illness**

Patients described an adaptive process of reshuffling hopes and dreams in relation to the process of healing within the context of their dynamic clinical status (stable, improved, or deteriorating). Patients learned to hope in new ways associated with four categories: (a) facing the reality of the disease, (b) hope linked to the condition of the disease, (c) factors that enhance and reshape notions of hope, and (d) factors that unhinge hope.

Patients now seemed to face the reality of the diagnosis and accept the possibility of death (acceptance being one facet of the healing process) while hoping to maximize their life experiences (restoring purpose, another indicator of the healing process). One participant described how acceptance allowed her to hold short-term hopes: "I told myself that I knew I was going to die one day, so I needed to stop worrying [and] that I was going to live [with cancer] day by day. My stress level went way down and I was able to start making plans again and having hopes." Participants also described the effect of acceptance on their outlook, with one saying, "[Accepting the diagnosis] makes you want to maximize everything you have even more—even more than before."

Patients felt that they could continue hoping as long as their disease was stable or improved, with one participant speaking of the role of test results in maintain-

ing hope: "Finding results that are either positive or the same is hopeful, and, so far, I haven't had any negative reports . . . so that's always hopeful." Hope was diminished with disease progression, as another individual explained, "What does diminish the hope is if you get a bad result. That really crushes it. Like my last result was not a good result, so, you know. That day I went straight home." Although the general trend showed increasing levels of hope, patients described how their illness influenced the "highs and lows" of their hope.

Patients identified factors that enhanced notions of hope, such as receiving active treatment. One participant said, "Based on these treatments, I am hoping to gain a few years. I know I won't get that much more, but a few years would suffice me." Patients also described protecting themselves from unrealistic hopes, with one saying, "I don't think it's good to hope for the impossible or even the improbable, [because] that's just going to bring you down when it doesn't come true. . . . Sometimes it does! But that's the exception, not the rule." Reflecting on the past hardships they had overcome provided feelings of empowerment and hopefulness, as did focusing on "the smaller things in life," with one participant explaining, "It's been a couple [of] months that I have started appreciating the smaller things in life. That I find small moments of happiness and, through them, small hopes." Incorporating normalizing activities from their life prediagnosis also seemed to generate new forms of hope.

Hope was still vulnerable to disruptions along the way. Patients described uncertainty and hopelessness at various points in their journey from a perceived lack of instrumental or emotional support. Uncertainty regarding insurance coverage was one example of a perceived lack of instrumental support. Regarding emotional support, patients spoke of a perceived lack of empathy from healthcare professionals or a lack of positivity and sensitivity from their social support networks, with one participant explaining, "Well, I was completely hopeless. There was no more hope. I was sure of dying with what they [the doctors] told me. Tell me, how could I have had any hope?"

### **Strengthening the Link Between Hope and Wellness**

Patients readily identified the relationship between hoping and living in wellness, describing a positive feedback cycle of feeling hopeful while in states of wellness and using wellness as a context for hoping. As a result, the need to protect their hopes was primordial to patients. This final theme was characterized by two categories: (a) believing in the hope-wellness cycle, and (b) protecting hope with the goal of living in wellness.

High levels of hope were deeply interwoven with living in wellness (i.e., hope-wellness cycle) according

to patients, with one explaining, "I think that if you are in well-being . . . that allows you to have hope. If you don't have well-being and you don't feel good within yourself, then I don't think you can have hope." Patients often defined their newly formed hope as hoping for a future that encompasses their present state of wellness. One participant said,

Well, really we live in the present, right? So I think hope is always . . . I mean, it's about the future, but what most people always hope for in the future is to have the life that they have in the present, if they are enjoying their life. Or, at the very bottom line, you hope it won't get worse.

Patients often used this present state of well-being as a context for hoping to accomplish short-term goals, such as trips to visit loved ones. In addition, they hoped "for a longer time to live with a good quality of life," highlighting the full circle of the hope-wellness cycle.

Realizing the importance of a hopeful way of being, patients described a number of ways in which they protected their newfound hopes and, in turn, wellness. Patients actively reflected on the process, the changes they had made in their lives, and their hope that these changes continued. In addition, patients illustrated the importance of maintaining a positive inner world by blocking out the negativity, with one participant noting, "I will start to let negative [thoughts in my head] and destroy this hope that I have now. But I want to power through. I don't want to think of those." Patients also actively sought a positive frame of mind. One participant said, "I do a lot of, like, imaging . . . picturing positive outcomes all the time." In addition, they identified the importance of surrounding themselves with authentic relationships to promote a positive frame of mind, as this participant explained.

Throughout my life, I have created links with people, and now I see them bearing fruit. Sometimes, we aren't always inclined to think that a person can bring you a lot in times of hopelessness. So, it's a learning [opportunity]. It really is a personal growth for everyone.

Finally, the positive effect of finding a patient-centered, holistic approach to care allowed patients to feel that their hopes were protected. As one participant explained, "It provides a lot! It provides hope! Just all the attention and the way the patient is handled as well. It's very sensitive and it's very good. It doesn't exist. . . . I'm sure it doesn't exist in lots of domains."

## Discussion

The current study appears to show a dynamic interaction between hope and healing in patients with

NSCLC. In this study, hope was linked with various phases of the healing process, such as accepting a new reality, finding meaning, and achieving wholeness. In addition, the patients described hope in relation to their wellness, with implications for the care nurses provide patients. The current study adds to the literature by describing ways in which hope and healing are intertwined and rebuilt together through the process of restoring meaning, purpose, and wholeness in patients living with a life-threatening lung cancer diagnosis.

## The Vicissitudes of Hope

Patients describing the dynamic nature of their hope as it fluctuates in response to a number of factors in their lives is consistent with the literature, where hope is viewed as a multidimensional and changing process (Dufault & Martocchio, 1985; Farran, Herth, & Popovich, 1995). Hope is an essential experience of the human condition (Farran et al., 1995). Patients in the present study continue to experience cycles of hope, loss, and reconstruction after they have recovered from the initial shattering diagnosis. This study furthers an understanding of how patients experience cycles of diminished or increased hope within the context of their illness trajectory. To the best of the authors' knowledge, no other studies have described the vicissitudes of hope in terms of the various barriers and facilitators present as patients learn to live in an uncertain new life.

**The illness trajectory context:** The ability of patients to enhance and reshape notions of hope in relation to healing was situated within the context of the illness trajectory. The condition of the disease as stable, improved, or deteriorating seemed to influence the nature of the patients' hope, reinforcing previous findings (Benzein, Norberg, & Saveman, 2001; Buehler, 1975; Chi, 2007). Nonetheless, quantitative studies have failed to show a change in hopefulness in response to the phase of illness. Rather, studies suggest that the perceived efficacy of the treatment is significantly correlated with levels of hope (Chen, 2003; Herth, 1990; Stoner & Keampfer, 1985). This calls for healthcare practitioners to be sensitive to the ups and downs of hopefulness that patients tend to experience.

**Facilitators:** Participants described numerous factors that seemed to enhance and reshape their sense of hope, including receiving treatment, protecting oneself from unrealistic hopes, surmounting past hardships, emphasizing smaller achievements, and incorporating parts of their old lives within the current clinical context. In addition, patients seemed to protect their hope by striving to live in wellness, reflecting on and feeling a shift in their approach to life, maintaining a positive inner world, surrounding themselves with a supportive network, and receiving patient-centered, holistic care. Similarly, these facilitators have been identified as strategies commonly

used to maintain hope in a comprehensive literature review (Chi, 2007).

Incorporating parts of the patient's life prediagnosis into one's current reality has been referred to as maintaining normalcy, according to a qualitative study in which a sense of normalcy was associated with hopefulness (Hinds & Martin, 1988). Although patients in the Hinds and Martin (1988) study used normalcy as a way of visualizing themselves in a more hopeful future, patients in the current study emphasized a different purpose for maintaining normalcy. In trying to incorporate their past life into a new self-paradigm, they seem to be hoping to enjoy life in the present. This hope is related to striving for wholeness, which is one outcome of the healing process (Erickson, 2006). Therefore, hope in the present appears to be an important proponent of healing for patients in this population.

To the best of the authors' knowledge, surmounting past hardships as well as reflecting on and experiencing a shift in approach to life have not been previously identified as important factors for enhancing or reshaping patients' hope. Given individuals' innate healing potential for learning and growing in the face of hardship, these findings suggest that healthcare professionals must work to understand the ways in which their patients may have overcome past obstacles to help bolster hope, healing, and the transcendence of suffering in the present (Erickson, 2006; Mount, 2003; Mount et al., 2007).

The fact that pursuing, practicing, and surrounding oneself with holistic care is hope-promoting for patients in the current study is supported in the literature (Downer et al., 1994). Patients seek to heal in all domains of their lives beyond the biophysical, and that goal seems to contribute to their hopefulness. This has important implications for practice, highlighting the need to establish an integrative model of practice to optimize care and treatment for the whole patient (Grossman et al., 2012).

**Barriers:** The patient's hopefulness seems to be subject to a number of hurdles in terms of variable instrumental and emotional support in this study. Changing treatments, illness progression, and difficulties receiving medication insurance are noted as some factors that negatively influence instrumental support and, therefore, hope. This is similar to findings in another study where prolonged and seemingly ineffective treatments caused patients to lose hope (Lin et al., 2003). The literature reports illness progression to also exert deleterious effects on healing by causing spiritual suffering (Chio et al., 2006).

The finding that a lack of emotional support from the healthcare team, family, or friends seems to unhinge hope is consistent with previous literature identifying abandonment and isolation as hope-hindering experiences (Buckley & Herth, 2004; Herth, 1990). The

importance of supporting and educating healthcare professionals, families, and friends to maximize their sensitivity and beneficial influence on patients' hope has been previously discussed in the literature (Tan & Karabulutlu, 2005). Perceived lack of emotional support from the healthcare team and negative or lack of communication harmfully affect hope and healing (Dobkin, 2009; Ferrell & Coyle, 2008; Thorne, Hislop, Armstrong, & Oglov, 2008).

The current study reinforces findings on the integral role that hope plays in patients' lives. Patients need to feel hopeful following a shattering diagnosis and while living with a life-threatening illness (Chi, 2007; Moore, 2005; Saleh & Brockdopp, 2001). These findings provide a new lens through which patients with lung cancer experience the ups and downs of hope, sparked by a variety of hope facilitators and barriers, and how many of those also affect healing. The study adds to the literature by exploring how individuals living with advanced lung cancer appear to navigate uncertainty and continue to hope for the future. Owing to the shifting focus of hope over time, healthcare professionals need to be sensitive to such changes when discussing the patients' hopes (Clayton, Butow, Arnold, & Tattersall, 2005).

## Hope and Healing

The current study's findings suggest that hope and healing are related at a number of points along the illness trajectory. This link appears to be most evident during the phases of diagnosis, transitioning out of the morass of shattered hope, and the process of reframing hope within the new context of a life-threatening illness. In these phases, healing seems to be reflected by the patients' ability to find meaning, accept the diagnosis, and experience a sense of well-being (Erickson, 2006).

The life-changing and hope-shattering experience of receiving an advanced lung cancer diagnosis was reported by all participants in this study, corroborating previous research on the topic (Feldman & Snyder, 2005; O'Connor, Wicker, & Germino, 1990; Ramfelt, Severinson, & Lützén, 2002; Thompson & Janigian, 1988). That distress has been shown to shatter patients' understanding of the world as they knew it and their place in it (Erickson 2006; O'Connor et al., 1990; Ramfelt et al., 2002; Thompson & Janigian, 1988). That world view is also known as a life scheme, or a cognitive representation of one's life. It organizes "one's perspectives of the world and oneself, goals one wishes to attain, and events that are relevant to those goals" (Thompson & Janigian, 1988, p. 260). The current study seems to suggest that the patients are working toward a new world view that encompasses clinical realities, as well as goals and meanings.

The feelings of distress, hopelessness, and overwhelming losses indicate a need for healing to restore the patients' sense of wholeness (Cassell, 1982; Egnew,

2005, 2009; Erickson, 2006). That healing process has a physiologic explanation that can be elucidated from an integrated mind-body perspective (McEwen, 2008; Pert, Dreher, & Ruff, 1998). Negative emotions such as distress and hopelessness inhibit innate physiologic processes of healing that can lead to diverse chronic illnesses and mortality (Miller, Ancoli-Israel, Bower, Capuron, & Irwin, 2008; Thayer & Sternberg, 2006; Watson, Homewood, Haviland, & Bliss, 2005). Beyond the scope of this study, this biologic knowledge suggests that unresolved hopelessness and distress may limit patients' ability to heal, thereby inhibiting their potential to improve or even maintain their wellness before, during, and after cancer treatment.

A second link between hope and healing is seen when patients strive to pull themselves out of the emotional morass. Patients describe reaching a point of exhaustion, at which time a shift in their cognitive orientation seems to emerge. They report experiencing a form of acceptance, one of the desired outcomes of healing (Erickson, 2006; Mount et al., 2007). That acceptance seems necessary before they can start restoring a sense of order and purpose to their days through short-term, action-based strategies, such as writing their wills. These initial short-term goals seem to help patients regain their confidence in living to see tomorrow by accomplishing daily goals that are nonetheless future oriented. That ties into Hinds' (1984) definition of hope as the extent to which one believes in a "personal future" (p. 360). Although participants do not report having an active hope at this point, the short-term daily goals used to re-impose a sense of order and purpose appear to be integral to the transition to a new belief in a hopeful future.

Third, hope and healing are intricately linked in the dynamic process of reframing hope within the new context of a life-threatening illness. Patients spoke of transitioning from the hopelessness brought on by diagnosis to acceptance and a restored sense of order and purpose, the foundation of meaning in life. Feldman and Snyder (2005) proposed that hope is a component within the overarching concept of meaning in life. In contrast, the current study's findings describe how the structural components of meaning (order and purpose) are used to lay the foundation for new ways of hoping.

In addition, the participants' journeys from hopelessness to hope seemed to be built on key elements of healing—a sense of order, purpose, and meaning that helps the patient transcend his or her suffering within the context of illness. That echoes Erickson's (2006) position that "healing helps one bridge the gap between loss and self-discovery" (p. 414). Hope seems to be rebuilt in conjunction with healing through order and purpose (the structural components of meaning).

To the best of the authors' knowledge, needing to reach acceptance before allowing oneself to lay down

## Knowledge Translation

Healthcare team members need to be sensitive to the fluctuating nature of hope and its relationship with healing.

Nurses and other professionals should be aware of their effect on the hope and healing process of patients.

Patients experience high levels of distress and suffering, indicating a need to heal.

the foundation for a new hopeful future has not been reported in the literature. The relationship between hope and leading a meaningful life seems to be triggered by initially imposing order and purpose to one's day, which has not been reported elsewhere. Although Thompson and Janigian (1988) have discussed the disruption caused by a life-threatening diagnosis and the importance of restoring a new order and purpose to allow for a meaningful future, the concept of hope is not explicitly addressed. Orientation toward the future is an intrinsic element of hope (Feldman & Snyder, 2005). The current study's findings that patients use the structural components (order and purpose) of meaning (one of the desired outcomes of healing) to help themselves live day by day before being able to envision a more long-term hope adds to the literature by describing a more complex link between hope and healing.

## Implications for Practice

Suffering is an intrinsic part of the human experience, particularly in times of illness (Ferrell & Coyle, 2008). Living with lung cancer is particularly distressing (Cooley et al., 2003; Tishelman et al., 2005; Zabora et al., 2001). The public association of cancer and death tends to impede healing, which is where the healthcare team, particularly nurses, is crucial (Cassel, 1982; Ferrell & Coyle, 2008). Nurses play a pivotal role in helping patients decipher medical information while also humanizing the experience of care (Ferrell & Coyle, 2008). Egnew (2009) wrote about physicians' responsibility to realize their full potential as "physician-healers" (p. 170). This onus to heal should not solely rest on the shoulders of physicians but of all members of the healthcare team. Nurses and members of the healthcare team need to embrace their important roles as healers because a sense of interconnectedness, feeling supported, and being known are elements of regaining wholeness and healing (McElligott, 2010).

An integration of healing in care, particularly cancer care, not only benefits the patient, but may also make cancer a less distressing diagnosis and help healthcare professionals regain a deeper sense of appreciation and satisfaction with what they do (Dobkin, 2009; Egnew, 2005, 2009).

In addition to advocating for a larger focus for healing in practice, the current study adds to the literature in describing the relationship between hope and healing. The findings suggest that fostering hope in patients is essential within the clinical realities of the situation. Although all patients agreed that they did not want to feel “lied to” by the healthcare team, the ability to hope on a day-to-day basis as well as a more future-oriented hope were essential to their ability to feel well in the present. This knowledge needs to be used by healthcare professionals because of the known physiologic ramifications of feeling unwell, such as feelings of hopelessness, despair, and distress (McEwen, Eiland, Hunter, & Miller, 2012; Pert et al., 1998). The study findings support previous research on how healthcare professionals foster hope by being tactfully honest with patients when discussing the future and promoting patients’ hope (Clayton et al., 2005; Hagerty et al., 2005).

Healthcare professionals need to be mindful of the whole person, not simply its fragmented parts, by helping to navigate the clinical context, assisting in the search for meaning and the rebuilding of hope, and being companions at each step of the healing journey (Cassel, 1982; Dobkin, 2009; Egnew, 2009; McEvoy & Duffy, 2008).

### Limitations and Future Directions

The current study is subject to a number of limitations, owing to a need for additional research in the area of hope and healing in patients with lung cancer. This study asked patients to reflect on their experiences, so future research might consider a longitudinal design to better follow patients throughout their experiences to explore the changes in hope related to time since diagnosis and treatment phase (e.g., at diagnosis, during active treatment, after active treatment). In addition, future studies might take a more quantitative approach to describe and verify the vicissitudes of hope. That being said, the widely used Hope Scale (Feldman & Snyder, 2005) imposes limitations on the dynamic nature of hope. This calls for a need for reevaluating the use of hope as a fixed variable. In addition, although this study was able to describe the dynamic nature of hope throughout the healing process specific to patients with lung cancer, future studies might explore the applicability to other populations by focusing on or including patients with various life-threatening diagnoses. Finally, because of the sensitivity of the topic, patients in this study were preselected based on their level of emotional distress at the time of recruitment,

potentially limiting the understanding of hope in more vulnerable and highly distressed patients.

A future study might explore whether hope and healing have a symbiotic relationship in which both may be shattered by the experience of cancer but rebuilt together through influencing and being influenced by one another. The current study’s data suggest that hope and healing do not exist in isolation from each other. Rather than hope existing within healing, they seem to intersect at the level of meaning (i.e., through the structural components of meaning, order, and purpose).

The relationship between hope and healing is grounded in the sharing of barriers and facilitators but also in the familiar structure of order and purpose. Initially, order and purpose were used to support the individual’s move toward a new sense of future orientation, then a new sense of meaning (an outcome of healing) and hope. The findings raise the question of the role of order and purpose as possible mediators of the relationship between hope and healing. That question was beyond the scope of this study but would be important to explore in the future.

### Conclusion

Patients in the current study described their hope and healing as a dynamic experience leading toward a sense of acceptance, wholeness, and meaning in their lives. The structural components of finding meaning (e.g., order and purpose) were used by the patients in this study to find new hope and new meanings—and, therefore, heal—within the changing context of their clinical reality. This study suggests that patients may need assistance in finding and reframing meaning within their new life paradigm not only to assist the process of rebuilding hope but also to promote healing. All healthcare professionals, particularly those working with a population known to be vulnerable to a loss of hope (e.g., patients living with an advanced lung cancer diagnosis), should be mindful of the importance of hope, its detractors and facilitators, and its relationship with healing.

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