The Challenge of Existential Issues in Acute Care: Nursing Considerations for the Patient With a New Diagnosis of Lung Cancer

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A new diagnosis of lung cancer is a highly threatening experience that raises personally relevant existential issues and brings death-related thoughts and concerns to mind. Those issues can be very disturbing to patients, leading to distress and potentially to a lowered quality of life. The purpose of this article is to present to the practicing oncology nurse the types of existential and death-related concerns that patients with a new diagnosis of lung cancer may have. In addition, the article identifies practical strategies and resources for oncology nurses who can help patients accept and manage the normal but often distressing responses to a life-threatening diagnosis.

Cancer is an alienating and existential experience. I know of no other common disease that immediately causes so much fear, anxiety, depression, confusion, and sense of impending disaster in a patient or his or her significant others as when they hear the word cancer for the first time (Krelstein, 2010, p. 657).

—Murray Krelstein, patient

Lung cancer is the leading cause of cancer death and the second most common cancer among men and women in the United States (Siegal, Ward, Brawley, & Jemal, 2011). A new diagnosis of this life-threatening disease has a broad impact on a person’s emotional, cognitive, social, spiritual, and physical well-being (Hill, Muers, Connolly, & Round, 2003; Rolke, Bakke, & Gallefoss, 2008). Although lung cancer carries an overall very poor prognosis, little attention has been given to understanding and addressing existential concerns among newly diagnosed patients (Lehto & Therrien, 2010). That problem is particularly relevant as it relates to individuals who are facing early-stage disease, a group that is growing with longer anticipated survival secondary to the earlier detection and access to improved treatment methodologies (Molina, Yang, Cassivi, Schild, & Adiel, 2008). The purpose of this article is twofold: to present to the practicing oncology nurse the types of existential and/or death concerns that patients with a new diagnosis of lung cancer may have, and to identify practical strategies and resources for oncology nurses who help patients accept and manage the normal but often distressing responses to a life-threatening diagnosis.

Background

The term existential is defined as “of or relating to existence” in various dictionary sources. The term has been more fully developed in philosophical and psychological schools of thought that focus on the condition of human existence. Of primary concern to existential scholars and researchers is an individual’s actions, personal responsibilities, pursuit of life meaning and purpose, and overarching human concepts of personal freedom, alienation, making sense of suffering and death, regret, and choice (Yalom, 1980). Existential concerns, which arise while actively wrestling with the knowledge and potential imminence of personal death, are normal and common and can be a significant source of distress among individuals facing a life-threatening diagnosis regardless of the type of illness and the cultural background of the person (Henoch & Danielsen, 2009; LeMay & Wilson, 2008; Leung & Esplan, 2010). Existential
issues can be evoked by physical and psychological concerns, and surface when self-identity is threatened (Henoch & Danielsen, 2009). How people resolve existential issues will differ individually, with some people finding solace in spiritual and religious sources, while others do not (Udo, Melin-Johansson, & Danielsen, 2010; Yalom, 1980).

Clinical focus on existential and death-related concerns in individuals with cancer largely stem from palliative care and have been aimed at assisting patients with a terminal diagnosis manage psychological and physical symptoms at the end of life (Breitbart, Gibson, Poppito, & Berg, 2004; Fitzsimmons et al., 2007). Individuals in medical-surgical environments who are facing life-threatening illness often feel alone with their issues, and healthcare providers who are uncomfortable addressing end-of-life and death-related issues contribute to this alienation (Fitzsimmons et al., 2007). LeMay and Wilson (2008) identified that individuals who have difficulty finding meaning and purpose in their lives have regrets and concerns about the past, possess anticipatory death concerns, have higher religious worry, and are more likely to experience existential distress, a condition characterized by despair that may heighten desire for death and even contribute to suicidal ideation. However, people who overcome existential challenges may experience end of life as a time of enhanced relationships with loved ones, a deepening sense of self, and heightened psychological growth (LeMay & Wilson, 2008).

Less attention has been given to the existential-related concerns that individuals facing a new diagnosis of a life-threatening disease (e.g., lung cancer) may have in the acute care treatment setting. That lack of attention is puzzling given the ubiquity of such concerns that surface when people are told that they have cancer (Leung & Esplan, 2010; Weisman & Worden, 1976–1977). However, psychological symptoms such as anxiety and depression are well documented in individuals newly diagnosed with cancer (Jacobsen & Jim, 2008; Osborn, Demoncada, & Feuerstein, 2006; Stanton, 2006). In addition, subsets of patients with cancer are shown to persist with psychological difficulties long into the survivorship spectrum (Stanton, 2006). In a large sample of patients with cancer (N = 4,496), psychological distress rates were 35% (n = 1,578) for the overall group and 43% (n = 273) for the subset of patients with lung cancer (N = 629) (Zabora, BrantzenhofeSzoc, Currow, Hooker, & Piantadosi, 2001). In that study, psychological distress was defined more broadly and included a global measure of anxiety, depression, somatization, and hostility parameters (Zabora et al., 2001). Interventions for psychological distress (e.g., anxiety, depression) are multifaceted. Mental health referrals can be made, and treatment may include psychotherapy or pharmacotherapy. Types of psychotherapy used for patients with cancer to manage psychological distress include cognitive-behavioral-type treatments that focus on altering thought patterns that are maladaptive and contribute to emotional distress, professional counseling, psychoeducational treatments, cancer support groups, and problem-solving therapies (Jacobsen & Jim, 2008; Osborn et al., 2006). In addition, complementary and alternative therapies such as guided imagery, relaxation training, mindfulness meditation, and music therapy have become increasingly popular for managing symptoms, including psychological distress in patients with cancer (Molassiotis et al., 2006; Wells et al., 2007). One limitation of the research that has examined the efficacy of mental health interventions in cancer is that the studies have been conducted primarily in women with breast cancer (Stanton, 2006). In a systematic review of treatments used for improving well-being and life quality for patients with lung cancer, the interventions that were successful permitted the patient to develop a therapeutic and empathic alliance with the health provider (Thompson, Sola, & Subirana, 2005). As noted in other studies, interventions during the early postdiagnostic phase of lung cancer focused on coping skills and treatment management, whereas the patients in the terminal phase of illness received existential-oriented intervention (Thompson et al., 2005).

Importantly, individuals with cancer who present with psychological distress often have underlying death anxiety and may engage in behaviors such as seeking information that distracts focus from existential-related concerns (Yalom, 1980, 2008). In addition, healthcare providers who have death-related anxiety themselves can be reluctant to discuss existential or death-related concerns with patients and their families (Defnner & Bell, 2005). Clinicians may want to avoid the burden of emotional involvement in a fast-paced health environment that does not support or may even trivialize the importance of building human relationships (Leung & Esplan, 2010). Therefore, time constraints may limit availability and amount of exposure with patients, both of which are necessary to build trusting therapeutic alliances. Patients may expect nurses or their physicians to take the initiative in discussing their deep fears and concerns, whereas the providers (particularly in the acute care setting) may be focused on disease treatment and management (Leung & Esplan, 2010). However, individuals may experience difficulties focusing attention on treatment-related information if they are consumed by emotional topics such as how much time they have left or how their loved ones will manage when they are gone. Therefore, despite the inherent barriers that are established based on health environment and patient-provider communication factors, it remains essential that nurses are comfortable in assessing for and discussing existential concerns following diagnosis and during early treatment for lung cancer.

Methods

Death concerns were gleaned from semistructured interview content derived from 75 men and women recruited from the Veterans Administration Health System and a regional cancer center, both in the midwestern United States, who had a new diagnosis of non-small cell lung cancer and who were preparing for treatment. The institutional review board and research development committees at the respective institutions approved all study procedures. The major research findings from the study are reported in Lehto and Therrien (2010). The majority of the individuals (n = 66, 90%) had either stage I or II disease, and seven (10%) had stage IIIa disease. The participants all
were adults aged 21 years or older (X age = 64.98, SD = 9.28, range = 47–83) with a mean education of 12.74 years (SD = 2.28, range = 8–20). Eligibility criteria for the study included that the participants were aged 21 years or older with a new diagnosis of limited-stage non-small cell lung cancer and able to read and write English to achieve the study requirements. Potential volunteers were excluded if they had a history of cancer or lung cancer recurrence; cognitive or psychiatric disorders; history of advanced cardiac, respiratory, renal, or other disabling medical disease; or current use of psychoactive medication that could impair study participation.

The semistructured interview used the Conceptual Content Cognitive Map (3CM) method to gather data related to the individual's perceptions and concerns following a new lung cancer diagnosis during the early pretreatment period. The 3CM is an established procedure used to measure perceptions and thought contents while providing a mechanism for participants to explore the important issues in their minds (Kearney & Kaplan, 1997). Participants are asked to think about and write down important concepts related to an issue or problem on separate cards, and then to arrange the specified concepts in a way that makes sense to them. No restrictions are placed on how many items are listed or how the content is organized. The 3CM has useful application for examining research problems where less is known about an individual or group’s perceptions and information is needed to make decisions and to determine appropriate action plans. The method has established early construct and concurrent validity (Kearney & Kaplan, 1997). The 3CM provided a method for examining and gaining understanding of illness perceptions and concerns of the participants who were facing a new diagnosis of lung cancer. Participants wrote down the important concepts that came to mind about the cancer diagnosis on note paper. They then coded the content with positive (+) or negative (–) symbols for affect associated with the specific content.

The results were quantified by content analysis and the development of categorical themes that emerged from the data based on groupings of related statements. Contents were quantified and qualitatively analyzed for substance. Inter-rater reliability of the coding scheme was achieved between two nurse scientists who independently analyzed, summarized, and coded the 3CM content (Lehto & Therrien, 2010).

Types of Existential Concerns

The focus of the interviews was aimed at understanding patients’ perceptions and concerns about the illness experience. Among the patients, death-related issues were cited by 53% (n = 39), existential-oriented future disease fears were cited by 66% (n = 48), and spiritual-oriented content was identified by 22% (n = 16) of the sample, demonstrating the importance of such content to individuals facing lung cancer. The areas of concern included (a) psychological preparation, (b) time left to live and loss of a productive future, (c) impact of death on loved ones, (d) behavioral preparation, (e) death acceptance, (f) experiences with others who have died from cancer, and (g) post-death issues. Existential-oriented future disease fears included concerns about an uncertain future, the potential for disability, and the possibility of disease spread. Spiritual-based content included religious practice and prayer, life purpose, and a sense of a larger purpose (Lehto & Therrien, 2010).

Death-related anxiety and existential concerns affect individuals facing cancer who remain physically healthy, but who are vulnerable because of the nature of the diagnosis, the stressful hospital environment, the experience of unpredictable circumstances, and previous death encounters among friends and family. Addressing such concerns during the early pretreatment phases of illness may assist individuals while they remain physically healthy to explore their responses to the illness in a life-enhancing direction (LeMay & Wilson, 2008).

The Role of the Nurse: Strategies and Resources

Although existential distress is not identified as an accepted nursing diagnosis, death anxiety is listed and specific interventions are cited (Carpenito-Moyet, 2008). However, the identified nursing interventions for death anxiety are focused on helping people who are facing imminent death. Strategies such as exploring life stories, relationships, spirituality, advance directives, and symptom management are identified as appropriate nursing interventions in the setting. However, having discussions related to existential and death-related concerns may be uncomfortable for oncology nurses in the acute care setting who could be concerned that such communication will increase psychological distress for patients. Therefore, patients who are preparing for or are receiving treatment for early-stage lung cancer may not have existential and death-related concerns addressed because the healthcare providers are focused on curative treatments and disease management. Strategies for nurses are needed that can offset or reconcile death-related concerns among individuals facing procedures such as surgical lung resections during acute treatment processes. By addressing existential issues and death-related concerns early, nurses will be better able to determine individualized needs for mental health or other supportive interventions or services.

Interventions to Help Patients With Specific Areas of Concern

Psychological preparation: Psychological preparation is reflective of actively coming to grips with the reality of personal death.

Information on End-of-Life Concerns

Many patients with cancer facing the possibility of impairment or death from their diagnosis confront issues regarding financial and legal burdens on family members and loved ones. Strategies such as making funeral and burial plans, granting a power of attorney, and updating wills all are important aspects at this stage. Resources related to those concerns are available for healthcare providers and patients at the following Web sites:

- American Cancer Society
  www.cancer.org/mycancernet/Midwest/ProgramsandServices/american-cancer-society-navigator
- American College of Physicians
  www.acponline.org/patients_families/end_of_life_issues
- National Cancer Institute
  www.cancer.gov/cancertopics/coping/financial-legal
and the awareness that the treatment might not be effective. Similar to what Janis (1985) termed the “work of worry” in his seminal work conducted among patients facing surgery, psychological preparation likely helps facilitate cognitive integration of the life-threatening illness. Being able to integrate a potentially life-shattering event such as a diagnosis of lung cancer into one’s life perspective in a way that makes sense and provides meaning is integral to coping and to ultimate resolution of the stressor (Frankl, 1985). A first step involves helping patients to recognize that they are not alone (LeMay & Wilson, 2008).

Resources to help facilitate that process include the provision of clear and only relevant information, taking time to listen and to understand the situation from the patient’s point of view, and tailoring communication in accordance with the patient’s understanding. Such interventions require that the nurse be sensitive to developmental, experiential, cultural, and age-related nuances that can lead to individual variability in how a life-threatening diagnosis is integrated.

**Time left to live and loss of a productive future:** Patients facing treatment for lung cancer may be concerned about life expectancy and the anxiety-provoking anticipation of a limited future. For example, patients may feel sadness and anger about potentially not having the opportunity to see their grandchildren grow. In addition, patients may feel grief related to having a life that is not what they hoped. Facing a new diagnosis of lung cancer is very personal and can be a highly alienating experience. Patients who lack social support and intimate others in their lives to confide in may be particularly vulnerable in that regard. Helping patients access support groups that meet regularly or to find such resources via health-related social networking computer sites may allow patients to express feelings, find common bonds, and to find reassurance. In addition, nurses may be able to assist patients to consider their goals and values in the context of choosing priorities and using the time that they have left to live.

**Impact of death on loved ones:** If a patient is or has been the chief provider of his or her family, they may have concerns about how death will affect the family. Patients may be concerned about finding care for pets, for example, and other tangible and intangible consequences of how death impacts important others. In addition, patients may feel guilt and personally responsible for the burden that they are placing on significant others, particularly if they believe that their disease was self-inflicted by smoking. When patients are worried and anxious about the impact of their disease on their loved ones, being a supportive, nonjudgmental presence may promote an atmosphere of freedom where painful memories can be expressed. Negative emotions (e.g., anxiety, guilt) can be transformed to sources of meaning that promote well-being when patients feel comfortable and free to explore their vulnerabilities (Breithart et al., 2004).

**Behavioral preparation:** Behavioral preparation content refers to active strategies that the patient can take to make certain that essential life affairs are in order in case of death. Patients are cognizant that they might not survive surgery or that the disease might not be cured. Therefore, the priorities behind behavioral preparation are to offset the financial and legal burdens on the surviving family. Behavioral preparation strategies include such things as making funeral and burial arrangements, granting a power of attorney to act on the patient’s behalf if he or she were not in a position to make autonomous healthcare or legal decisions, and making or updating wills. Such activities are concrete action plans for managing an uncertain future and may increase peace of mind following a new diagnosis of lung cancer. The development of patient education materials that are easy to read and provide concrete direction for potential resources can supplement therapeutic interactions in the context of a trusting relationship. Topics on education resources may include direction for managing end-of-life affairs such as estate management and finances, support group location and resources, Internet resources, self-help references, and resources to assist family members who are affected by the diagnosis.

**Death acceptance:** When death acceptance is present at diagnosis, it likely reflects previous personal contemplation and integration of the reality of death and a finite existence. Trusting God’s will, maintaining hope, and surrender may coincide with death acceptance. Patients who accept death may want to discuss how they are approaching this potentiality. Some patients may find a renewal of value and even joy in living life when they are comfortable with the reality of their death (Browall, Melin-Johansson, Strang, Danielson, & Henoch, 2010).

**Experiences with others who have died from cancer:** Many patients who are newly diagnosed with lung cancer have past memories of experiences with friends or family who previously have died of cancer. Memories arise when the current situation reminds the patient of former encounters, and can be influential in activating thoughts and images about death from lung cancer. For the patient who has had life encounters that were frightening, such as interactions with significant others who experienced pain or suffering at the end of life, those thoughts can be particularly anxiety provoking. Building a trusting relationship where the patient feels comfortable discussing painful memories can be reassuring for the patient and may bring closure to those fears early in the illness continuum.

**Post-death issues:** Patients also may consider ideas about an afterlife at the time of a lung cancer diagnosis. Those thoughts reflect cultural knowledge about death and perceptions that death is not final. Spirituality content includes religious practice and prayer, life purpose, and a sense of a larger purpose. Belief in a positive afterlife and surrender to the unknowable future may palliate existential concerns (Udo et al., 2010). Conducting a spiritual assessment can alert the nurse to potential sources of strength that the patient may use to buttress their existential concerns. Recommendations for spiritual or religious resources can be made if the patient desires. However, patients may have negative perceptions and even anger toward religion. Listening and showing genuine respect for individual differences in perspective allow the patient both the freedom and permission to work through issues related to finding personal meaning and purpose for their life.

**Future disease fears:** Most patients who are newly diagnosed with localized lung cancer have concerns about the future, the
treatment, the possibility of disability, and the potential that the disease will metastasize. Some individuals are less able to tolerate uncertainty and, as such, experience much higher levels of potentially disabling worry in situations that lack structure, are uncontrollable, and carry potentially threatening outcomes (Dugas, Buhr, & Ladouceur, 2004). Providing reassurance and teaching concrete cognitive-behavioral strategies to reframe the situation and allay cognitive distortions may help patients to manage living with uncertainty (Shearer & Gordon, 2006). Assisting patients to focus their awareness on the current moment (e.g., through mindfulness practice) also may offset the worry and anxiety associated with uncertainty. Such interventions teach patients to identify and to disengage from negative patterns of thinking and to practice focused awareness and acceptance via meditation and breathing exercises (Hofmann, Sawyer, Witt, & Oh, 2010; Ledesma & Kumano, 2009). Relaxation strategies, such as hot baths, massage, yoga, music, exercise, and journaling to help alleviate anxious arousal also can be recommended (Shearer & Gordon, 2006).

As Weisman and Worden (1976–1977) identified in their seminal article on the existential plight in cancer, confronting personal mortality and managing the accompanying distress that surfaces from perceptions of powerlessness, regret, disappointment, anxiety, and life disruption are common and occur in varying levels of severity among individuals facing a life-threatening diagnosis. Reconciling that painful state is a process that unfolds over time and at different rates among people (Yalom, 1985). Patients who are experiencing distress about how their families will manage, who express unresolved grief, and who demonstrate high levels of negative affect secondary to existential and death-related concerns are likely to benefit from targeted mental health assistance. Referral in such cases may offset the risk to the patient of developing serious depression that could negatively impact long-term adaptation.

More formal strategies that are grounded in both clinical and empirical research have been applied to help individuals facing cancer manage existential distress (LeMay & Wilson, 2008). Those strategies often are implemented in the structure of support group therapy and are aimed at helping patients who are in the terminal phases of illness. Table 1 contains a listing of five recognized treatments. Such therapies are time intensive, require an organizational structure, often require a trained therapist to facilitate, and may be less available for oncology nurses who maintain a busy practice, particularly in noncomprehensive cancer center treatment settings. In addition, some of the therapies may not have systematic testing in groups with lung cancer. For example, cognitive existential therapy was developed for women with breast cancer (Kissane et al., 2003).

### Death Awareness and Education for Staff

Death awareness and education have far-reaching importance to oncology nursing practice. Identifying practical strategies that the oncology nurse can use to help patients accept and manage such concerns are essential. As direct care providers and as educators, oncology nurses are on the front lines in terms of assisting patients with managing difficult thoughts, feelings, and concerns. Importantly, research has shown that nurses who receive death communication education become more comfortable with discussion of life and death concerns with patients and their families (Deffner & Bell, 2005). Familiarity and comfort may be one factor for why discussions related to existential issues are more likely to occur in hospice and palliative care environments compared to acute care environments (Browall et al., 2010).

Close interpersonal relationships with patients and families can be burdensome to oncology nurses, a stressor exacerbated by finance-driven health care, high hospital patient acuity,

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**TABLE 1. Five Therapies That Address Existential Concerns in Cancer**

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<tr>
<th>Therapy</th>
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<tr>
<td>Supportive-Expressive Therapy (SEGT) (Yalom, 1980, 1985)</td>
<td>A therapist-facilitated support group that integrates key elements of existential psychotherapy to help patients manage illness-related and death-related issues. Patients are taught breath awareness, self-hypnosis, and cognitive-experiential exercises to facilitate expression. SEGT may be either short or long term and requires weekly 90-minute sessions.</td>
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<tr>
<td>Cognitive Existential Therapy (CEGT) (Kissane et al., 2003)</td>
<td>A therapist-facilitated support group aimed at helping women with early-stage breast cancer to live positive, authentic lives. Similar to SEGT, CEGT uses principles of Yalom’s (1980) existential psychotherapy (freedom of choice, responsibility, and confronting life) to teach cognitive-behavioral strategies for effective living. CEGT is comprised of 90-minute weekly sessions for 24 weeks.</td>
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<tr>
<td>Healing Journey (Cunningham, 2002)</td>
<td>Patients and families participate in either a formal or a self-help three-level step program. The first level requires four sessions related to coping with cancer and stress management. The second level (eight sessions) incorporates skills for healing such as meditation and journaling. The final level (eight sessions) incorporates existential concepts to help patients with spiritual healing and finding meaning.</td>
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<tr>
<td>Meaning-Centered Group Psychotherapy (Breitbart &amp; Heller, 2003)</td>
<td>The group therapy is based on Frankl’s (1985) principles of transcending suffering via finding purpose and meaning. The therapy strives to help patients confront their lives to build connectedness and to transcend suffering. The weekly sessions are 90 minutes for eight weeks.</td>
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<tr>
<td>Recreating Your Life (Cole &amp; Pargament, 1999)</td>
<td>The group therapy uses a cognitive behavioral and psychoeducation approach to help people live with life-threatening illness. The course has two formats: the first focuses on existential concerns and the second uses a spiritual view to help patients build connectedness. The two-hour weekly sessions occur for eight weeks.</td>
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shortened length of stays, high rates of nursing turnover, staffing shortages, and patient and family expectations (Barnard, Street, & Love, 2006). Nurses identified that finding time and a location for private discussion as well as staff attitudes can be barriers to establishing a dialogue related to existential issues (Browall et al., 2010). Such realities are challenging, and nurses working in acute care environments need to elicit support to ensure that time and space are available to engage in such discussions (Browall et al., 2010).

Oncology nurses also may personally experience death anxiety as they observe death, pain, and suffering in their clinical practice; a factor that may impede therapeutic interactions and discussions with patients about death-related concerns (Deffner & Bell, 2005; Lehto & Stein, 2009). Oncology nurses must examine their own thoughts, feelings, and attitudes regarding death and dying (Westman, Bergenmar, & Andersson, 2006). Knowledge and acceptance of death and dying can help decrease existential fears and can help a patient realize the importance of acknowledging and even preparing for death. Facing fear and managing disturbing, difficult emotions is challenging. In addition, by being a listening presence and by making effective connections with patients who are facing a diagnosis of lung cancer, care providers may find themselves experiencing similar disturbing emotions (i.e., sadness, fear, and feelings of attachment and helplessness). Some of those thoughts and emotions may be new and, therefore, surprising and confusing. Therefore, oncology nurses are first tasked with needing to recognize and understand how to cope with their own aversive thoughts and emotions. In that regard, seasoned oncology nurses also can share strategies that they have found effective to manage emotional sequela with more novice oncology nurses.

Scheduling even a few extra minutes in the context of a trusting relationship would allow time for the nurse to assess for existential or death-related concerns as part of the admission or pretreatment screening process. Existential and death-related concerns are of significance to the person facing early-stage lung cancer during the earliest illness phase. According to literature about the general nature of psychological distress among individuals with a new diagnosis of cancer (Osborn et al., 2006), nursing’s primary role in the targeted assessment and discussion of existential and death-related concerns cannot be underestimated. With many different types of interventions available to help patients manage a new lung cancer diagnosis, providers have an obligation to provide the most effective support to address the particular problem. Patients need to recognize that existential-related concerns are both common and normal, know that open discussion about such concerns is acceptable, and also perceive that oncology nurses and acute care team members are willing to confront the issues. An honest, willing, and receptive attitude among healthcare professionals to their own personal existential vulnerabilities can facilitate comfort in having such constructive encounters with patients. When resistance to accepting the reality of death is faced with compassion and openness, patients facing lung cancer can benefit from an improved quality of life and self-directed adaptation.

References


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