



CAP Lung Cancer Medical Writers' Circle

Facing Existential Issues Following a New Diagnosis of Lung Cancer:

The Patient's Perspective

Rebecca Lehto, PhD, RN

An unexpected diagnosis of a life-threatening illness such as lung cancer may increase vulnerability to disruptive and often painful existential concerns.¹⁻² For example, patients may find they are confronting thoughts about death, life's meaning and purpose, and are questioning why and/or how the illness happened. These types of thoughts can be distressing for patients with lung cancer who are recently diagnosed and are facing treatment. In this paper, research findings about the types of existential and death-related concern that patient's with a new diagnosis of lung cancer identified as they prepared for treatment are described. Patients with a new diagnosis of lung cancer may recognize some of these types of concerns in their own experience.

Most research that has examined death-related and existential concerns in people living with life-threatening illness has been conducted from a palliative care perspective with patients who are at the end of life.³⁻⁴ The research indicates that death-related and existential concerns are significant issues for these individuals despite cultural background and type of life-threatening illness.⁵⁻⁶ Studies report that individuals who are able to find resolution of existential concerns

may perceive better mental health, strengthened relationships with others, and expanded psychological growth and life meaning.⁵⁻⁶

Few studies, however, identify the nature of existential concerns in individuals who are newly diagnosed with lung cancer. Part of the reason may be that the primary focus of health providers is on preparing patients for medical and/or surgical treatment. Further, patients who are diagnosed with early stage disease may feel healthy and are continuing to lead active lifestyles. Patients may not feel comfortable discussing these types of concerns in this situation. Also, patients and health providers who have death anxiety may be reluctant to discuss existential and death-related concerns.⁷⁻⁸

In the research described in this paper, interviews were conducted with 73 patients related to the perceptions and concerns that they experienced following a new diagnosis of non-small cell lung cancer. The patients were generally healthy other than the new lung cancer diagnosis, and had not previously been diagnosed with other types of cancer. Most of the patients were eligible for surgery (55 total), and 18 were preparing for radiation and/or chemotherapy treatment. The interview method incorporated a procedure developed by Kearney and Kaplan⁹ that is used to gain information about how people frame a specific situation or problem. The patients were asked to list the important items that came to mind about the new diagnosis of lung cancer on post-it notes. They then identified if the contents they disclosed were positive and/or negative with a plus or a minus sign, and arranged the contents on paper in a way that made sense to them. Based on findings from these interviews, it was apparent that existential and death-related concerns were of importance to the patients facing treatment for lung cancer. Seven categories related to existential and death-related content were identified and are listed in accordance with their frequency: 1) psychological preparation; 2) time left; 3) impact; 4)

behavioral preparation; 5) acceptance; 6) cancer death experiences; and 7) post-death. Further, future disease fears such as concerns about an uncertain future, the potential for cancer spread, and disability were acknowledged by most of the patients. Contents related to spirituality and/or religion were also identified.¹⁰

Psychological preparation for the possibility of death was the most frequent type of death content. Closely related are disease fears and the concerns about the future that the majority of the patients disclosed. Such fears are reflective of the recognition of personal vulnerability, and uncertainties about whether the disease will be terminal. The post-diagnostic pre-treatment period is often a distressing time during which patients actively try to deal with the conscious awareness of the seriousness of the diagnosis and the potential that the treatment might not be effective. The process of accepting and integrating the life-threatening nature of the illness in one's mind can be alienating, and occurs at varying pace among patients. It may be difficult to focus on treatment-related information when these worries are on the forefront in one's mind. Therefore, it can be useful for patients to have a significant other person take notes during health care appointments if there are problems with concentration and memory. Further, it may be helpful to discuss these concerns with a health care provider such as the primary nurse. Restorative activities such as taking walks in nature offer opportunity for reflection and working through difficult thoughts. Spending time in natural environments may strengthen the attentional capacity needed to focus and concentrate, a cognitive resource that becomes fatigued but is essential to maintain when facing mentally demanding circumstances.¹¹

Patients identified concerns about how much time they have left to live. Some contents reflected sadness related to thoughts about loss, such as potentially not seeing grandchildren grow. Concerns about the impact of personal death included worries about no longer being

present as a chief financial provider, finding care for pets, and concerns about how death would affect family. Such worries relate to the potential for negative consequences on important others. Patients may find that open discussion with supportive friends and family may alleviate some of these types of concerns. There are cancer support groups that meet regularly where patients who share similar experiences can discuss their feelings and develop friendships. Nurses and social workers may have resources such as information about local support groups that can help in this regard.

Behavioral preparation refers to actual activities that the patient takes to ensure that important life matters are in order. Patients indicated that reducing financial and legal burden on survivors was a priority. Some patients reported making funeral arrangements. The importance of gaining a power of attorney that could act in the patient's behalf if they were no longer able to make independent health care or legal decisions was identified. Patients identified some of these contents as positive, suggesting that peace of mind could be associated with having such affairs in order. Internet resources with information about these topics are located at the end of this paper.

Newly diagnosed patients may think about past negative experiences with friends or family members who had died of cancer. Although not unusual, the activated memories surrounding cancer death may be negative and painful. It is important for patients to recognize that their personal experience is separate from what they have observed with other people who have died from cancer. If such memories lead to worrisome expectations, discussing them with one's health care provider is important.

There was also evidence of positive existential and death-related content. Some patients with a new diagnosis of lung cancer may have previously accepted the reality of personal death

prior to the current diagnosis. While the new diagnosis brought death thoughts to mind, the patients reported an attitude of positive acceptance. Patients also described thoughts about an afterlife that reflected cultural and/or religious learning, and beliefs about death and its meaning. Further, many of the patients identified spiritual and/or religious content such as religious affiliation and support, perceived higher order or purpose to life, and behaviors such as prayer and meditation as sources of strength.

Existential concerns vary in content among individuals, are often negative and distressing, and are relevant to the person facing a new lung cancer diagnosis. It is important that patients who are newly diagnosed with lung cancer recognize that these concerns are both normal and common. Patients may not feel comfortable discussing existential and death-related concerns when the focus is on disease recovery in an acute care environment. Further, it takes openness and courage for both patients and their providers to confront such issues. However, acknowledgement of personal vulnerability and the reality of death early in the illness continuum may promote enhanced self-directed adaptation and well-being.

The National Cancer Institute, American College of Physicians, and the American Cancer Society all have resources available for both health providers and patients related to a variety of cancer-related concerns. To learn more, visit:

- <http://www.cancer.gov/cancertopics/coping/financial-legal>.
- http://www.acponline.org/patients_families/end_of_life_issues
- <http://www.cancer.org/myacs/Midwest/ProgramsandServices/american-cancer-society-navigator>

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