Psychosocial Issues in Lung Cancer Patients (part 2)*

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Psychosocial Issues Related to the Disease and Its Treatment

Cognitive Changes and Neurologic Toxicity

Cognitive changes have been reported in lung cancer patients receiving chemotherapy with and without receipt of whole brain irradiation. Silberfarb et al.\(^2\) found impaired cognitive function in cancer patients receiving a wide variety of chemotherapeutic agents, regardless of the primary cancer site or whether there were metastases to the brain. In this study, depression and/or anxiety were not factors in causing the abnormal scores on cognitive testing. Since cognitive changes can be quite subtle and are often missed on routine medical evaluation, the authors suggested that brief neuropsychiatric testing be done prior to formulating a treatment protocol.

More recently, Kaasa et al.\(^2\) applied detailed neuropsychologic tests in non–small cell lung cancer patients with limited disease before and after treatment. The patients were randomized to chest radiotherapy or combination chemotherapy with cisplatin and etoposide. The patients receiving chemotherapy showed reduced neuropsychologic performance compared with those receiving radiotherapy; however, differences between the two groups were not statistically significant. A treatment-related effect on the central nervous system was suggested, possibly caused by the combination chemotherapy. In addition to the impaired cognitive function as a result of chemotherapy, there are some data to suggest that different chemotherapy regimens have variable effects on mood and affect.\(^3\)

Neurologic toxicity has been reported after combination chemotherapy and prophylactic whole-brain irradiation in patients with small cell lung cancer,\(^4\) possibly due to an adverse interaction between chemotherapy and radiation therapy. In 20 patients who were two- to ten-year survivors of small cell lung cancer, Johnson and colleagues\(^5\) found neurologic complaints in 75 percent, abnormal results of neurologic examinations in 65 percent, abnormal results of neuropsychologic testing in 65 percent, and abnormal computed tomographic scans in 75 percent. They concluded that neurologic abnormalities are common in long-term survivors of small cell lung cancer and may be more prominent in patients given high-dose chemotherapy during cranial irradiation or treated with large radiotherapy fractions. Laukkanen and colleagues\(^6\) completed a similar study in 12 patients with limited stage small cell lung cancer two years after treatment. Although all patients were capable of self-care, two thirds had posttreatment neurologic symptoms. The most common problem was recent memory loss. Half of the patients had subtle motor findings, principally minimal gait and coordination defects. The neuropsychologic impairment ratings were definitely impaired in seven of the 12 patients, with three borderline cases, and impairment was strongly associated with the extent of brain CT scan periventricular low-density lesions.

Important modifications have been made in the treatment strategy for patients with small cell lung cancer as a result of the increasing awareness of the neuropsychologic impairments associated with combined modality treatment (radiation and chemotherapy) directed at the brain. These modifications are a direct result of these and other systematic studies.

Fatigue

Severe and unremitting fatigue is one of the most common symptoms in lung cancer. Fatigue, which can be caused by the tumor as well as by chemotherapy
or radiotherapy, can occur at any time during the course of disease. Chronic fatigue can also be a physical indicator of a latent or manifest depression. Unfortunately, we know of no studies that have addressed this common manifestation of lung cancer.

Sleep Disorders

Sleep disorders are a common problem in cancer patients. In a study of psychotropic prescribing patterns at five major American cancer centers, in 1,579 cancer patients, 48 percent of the prescribed psychotropic medications were hypnotics and 44 percent were written for sleep, while 25 percent were given for nausea and vomiting and 17 percent were given for psychologic distress.97 Sleep disorders can be caused by disease and treatment-related symptoms (eg, dyspnea) as well as psychologic distress (eg, anxiety). As discussed earlier, uncontrolled pain is an important contributor to loss of sleep, and effective pain management may alleviate this problem. The functional performance and general well-being of the patient are also affected when there is a sleep disturbance. Despite the importance of sleep for the subjective well-being of the lung cancer patient, little research has been done on this subject. There has been some research on the pattern of sleep disturbance seen in lung cancer patients,98 but an earlier hypothesis that lung cancer patients have a different sleep architecture as compared with healthy controls has been rejected recently.99

Psychologic Distress

A wide range of changes in mood have been reported in cancer patients, from daily fluctuations in a "normal" range to psychologic disorders, such as chronic depression, phobic anxiety, and even psychotic disorders.100,101 To our knowledge, there are no comprehensive reviews on psychologic distress in lung cancer patients, although anxiety and depression levels are frequently measured. Some clinical reports refer to the potential underlying interactions between biologic and psychosocial processes, eg, manic syndromes in a patient with small cell lung cancer, apparently caused by ectopic corticotropin production.102

In a recent study with small cell lung cancer patients, Cella and colleagues103 examined the relationship of psychologic distress to a number of medical and demographic factors. In this large sample of more than 450 patients, a statistically significant relationship was found between the patient's performance status, extent of disease, and psychologic distress as measured by the Profile of Mood States,104 a patient-rated standardized measure of mood. Marital status, age, and level of education did not predict psychologic distress. The final regression index resulted in five levels of physical impairment that bear an approximately linear relationship to increasing levels of psychologic distress. This study suggests that the clinician can successfully use performance status and extent of disease to identify individuals with small cell lung cancer who are potentially at high risk for psychologic distress. However, these physical factors alone account for a very limited amount of the variability in mood disturbance (10 to 15 percent), and the authors suggest that other factors such as psychiatric history and social support may be important. The observation by Cella et al105 of a direct relationship between declining physical status and increasing symptoms of psychologic distress has been supported by other data on several different chronic diseases.74

In another report, Hughes106 evaluated the conditions of patients attending a chest clinic prior to the diagnosis of lung cancer. Symptoms of a major depressive illness were observed in 16 percent of 134 lung cancer patients before the establishment of their cancer diagnosis. This was a higher prevalence of depression than found in patients with nonmalignant chest conditions or healthy controls. Psychiatric history and present metastases were most significantly correlated with depression. At a subsequent examination of the lung cancer patients (two to three months later), a minority (16 percent) of a subsample (50 patients) with inoperable lung cancer had a major depressive illness. The author found that patients without any specific treatment were more likely to be depressed or dissatisfied.106

In lung cancer, it is especially difficult to discriminate between underlying biologic and psychologic factors causing depression. Depressive symptoms are frequently observed in patients with organic brain syndromes.107 In addition, the somatic symptoms of depression, eg, extreme fatigue and sleep disorders, can be confused with constitutional symptoms from the tumor or its treatment. Altered mood or behavior should not always be labeled as reactive or appropriate, and the clinician must consider the possibility of a severe and treatable depressive disorder. There has been only limited discussion of this issue in lung cancer patients.108

In our clinical experience, chemotherapy and radiotherapy can play a helpful role in the ability of some patients to adjust psychologically to a cancer diagnosis. First, tumor response to treatment can improve physical performance and alleviate symptoms; the extent of disease-related symptoms has been shown to correlate highly with subjective well-being.109 In addition, treatment is often associated with hope. This allows active efforts in dealing with the course of disease and helps some patients manage free-floating anxiety. In a sample of patients with different cancer sites, Cassileth et al104,109 found that treatment status was the most
important variable for prediction of anxiety. Patients receiving palliative care displayed significantly higher anxiety scores than did patients receiving active treatment or follow-up care.

Little research has been reported on psychotherapy in lung cancer patients. Several authors who studied the process of adjustment in cancer of the lung and other sites concluded that most of the patients cope fairly well with their disease. However, special attention has to be given to a high-risk group for poor psychosocial adaptation. Estimates of the relative frequency of this subgroup vary by author and tumor site. In lung cancer, we estimate that about 20 to 30 percent of patients would fall into this subgroup.

In addition to clinical variables, such as performance status and extent of disease, personal variables may contribute substantially to the patient's mood and level of distress. As the data in Table 2 (part 1 of this article) indicate, there may be subgroups of lung cancer patients who are strongly affected by depression and/or who do not express their needs and emotions. Psychosocial risk factors have generally been studied and discussed in regard to biologic end points. Regardless of the validity of the findings in the study of personality traits, personality factors must be taken into account when evaluating the individual patient's adjustment to disease and treatment.

**Social Interaction**

In clinical experience and empirical work (Table 2), lung cancer patients show a tendency toward social withdrawal. There are several possible explanations for this finding. Symptoms of the disease, especially impaired functional status, dyspnea, and pain, impose limitations on the patient's social life. Furthermore, many patients seem to dislike being dependent on others. It is unlikely that social withdrawal is unique for lung cancer in comparison to other chronic diseases. If it is, it is unlikely to be attributable to a "cancer personality," but more likely, it is attributable as a direct consequence of the disease.

Like every serious or fatal disease, lung cancer affects the patient's family and social environment. In a heterogeneous sample of 201 cancer patients and their relatives, Cassileth et al. found that patients' and relatives' scores on a number of psychologic measures were strongly correlated, despite large individual variations in scores. In that study, patients displayed greater mood disturbance but closer or more satisfactory emotional relationships than did their relatives.

A mutuality of psychologic response between patients and their families was also found by Goldberg et al. In a small sample of 20 lung cancer patients, physical status was closely related to subsequent depressive symptoms six months after diagnosis. However, in the spouses of these patients, depressive symptoms were more closely related to their degree of involvement in the social environment. Differing supportive care interventions may be necessary for the patient and spouse or next-of-kin. This is critically important for the patient with lung cancer, since the spouse is often the primary caregiver.

**Quality of Life**

When cancer treatments are curative, the short- and long-term side effects are usually outweighed by prolongation of disease-free survival (DFS) and overall survival (OS). When treatment is palliative, such as for metastatic non—small cell lung cancer, only modest prolongation in DFS and OS is anticipated, and therefore, the cost—benefit relationship between increased DFS/OS and treatment—related toxicity will vary from individual to individual. Ideally, the treatment toxicity should always be minimized, but even under the best of circumstances, it may be difficult for the clinician to estimate treatment benefit prospectively. Therefore, the patient's subjective experience is an important variable that is increasingly being used to estimate treatment benefit.

During the 1980s, there was a shift in psycho oncologic literature (Table 1). In the 1970s, general disease and treatment-related symptoms were studied, mostly in nonexperimental designs. However, in the 1980s, investigators began to integrate assessments of these symptoms within clinical treatment trials. Breast cancer and lung cancer are the most frequently studied cancer sites in this emerging area of research that is broadly labeled “Quality of Life” (QL) assessment. As evidence of the growing acceptance of this area of research, many cancer clinical trials cooperative groups have established study groups or sections that concern themselves with this area of clinical research. Quality of life has thereby become a widely used catch phrase and key word in clinical articles. Many have used this term to cover nearly all psychosocial aspects of cancer, studied with different research strategies. A comprehensive theoretical discussion of different QL concepts is beyond the scope of this section; however, more detailed discussions are available in several reviews and monographs.

Although most of us intuitively understand what the phrase “quality of life” connotes, it has been exceedingly difficult for social scientists, health services researchers, and clinicians to define precisely. Fortunately, there is increasing consensus on a definition of health-related QL. Most experts in this field perceive QL as a multidimensional construct that includes several important domains. These include functional status (performance of self-care activities, mobility, physical activities, and role activities such as work or household responsibilities); disease and treatment-related symptoms (specific symptoms from the disease such as pain or shortness of breath, or side effects of drug therapy such as nausea, hair loss, impotence, or
sedation); psychologic functioning (anxiety or depression that may be secondary to the disease or its treatment); and social functioning (disruptions in normal social activities). Additional considerations in the evaluation of QL may include spiritual or existential concerns, sexual functioning and body image, and satisfaction with health care.

Who should assess the patient's QL? Investigators are developing questionnaires that are completed by the patient, since ratings by an external observer may reflect the observer's personal point of view rather than the patient's subjective experience. Although there is a paucity of information about the specific psychosocial needs of lung cancer patients, there has been considerable interest in assessing the QL of this patient population. Some tools have been developed specifically for lung cancer patients. Other tools have been developed in heterogeneous cancer samples, but they have been applied to lung cancer patients.

In clinical practice, the development of a therapeutic plan is not based exclusively on tumor-related endpoints and prognostic factors. Most physicians consider the need for palliation and the possible toxicity of therapy when making treatment decisions. For such a complex task, physicians need more information than has been provided by the traditional prognostic factors and endpoints. In QL research, the patient's subjective experience of the disease and treatment is being studied in a systematic way. Information from this developing area of research soon will be available to assist physicians in working with patients in the process of clinical decision making. Introducing QL-oriented endpoints in clinical trials is a challenge for the near future, and lung cancer will probably continue to be an important disease in which these methodologic questions will be examined.

Discussion and Recommendations

Lung cancer and acquired immunodeficiency syndrome (AIDS) will likely be the most common chronic, life-threatening diseases in the early part of the coming century. As Stanley and Stjernswärd have noted, both of these diseases have some epidemiologic similarities. Neither disease was known at the beginning of this century, and now both are rapidly increasing worldwide, with the most prominent increases occurring in industrialized countries during the last decade. As smoking becomes part of the culture of developing nations, lung cancer will continue to increase in incidence. Lung cancer and AIDS are essentially preventable diseases, but influencing individual behavior by prevention and risk reduction programs seems to be very difficult. Environmental risk factors for lung cancer, which are more common in the occupational and living conditions of the lower social classes, have also been difficult to modify. The importance of prevention strategies for both lung cancer and AIDS will be likely to force an alliance between health professionals, behavioral scientists, and politicians during the next decade.

Health practitioners can play a key role in the implementation of smoking prevention in the individual patient. However, most physicians feel pessimistic about the effectiveness of their efforts. Recently, Kottke et al. in a randomized trial with family physicians, showed that asking a patient if he or she smoked increased cessation attempts one year later in 47 percent of those patients compared with only 36 percent in patients who had not even been asked about smoking by their physicians. Patients who had been asked if they smoked were more likely to claim to have stopped (13 percent) than patients who had not been asked (9 percent). It is worth noting that any given action—asking patients to give or to set a quit date, giving educational materials or a follow-up appointment—increased cessation attempts by about 10 percent. However, the rate of patients claiming continued abstinence (12 to 14 percent) was not specifically related to the physician's interventions. For successful long-term abstinence, the person who is quitting or has quit smoking will require an individualized, ongoing, and intense support program, as well as a reinforcing social environment.

Two other recent randomized studies strongly support these findings. An education program substantially changed the way physicians counseled smokers, and the availability of simple but specific mechanisms (chart reminders, nicotine gum) helped primary care physicians increase their success rates in helping patients quit smoking. The importance of the integration of psychosocial and behavioral scientists in smoking cessation strategies are clear cut.

As we have shown and summarized in Table 4, despite the high incidence of lung cancer in industrial countries, there is no systematic database on psychosocial issues for this disease. How would such basic information be useful? For the patient and his or her family, providing information on the psychosocial impact of this disease will assist and encourage them in their adjustment. In addition to the existential threat of a lung cancer diagnosis, there are many everyday problems and concrete needs that the patient and family will experience. Specific information about the impact of the disease and its treatment are essential for planning intervention programs and optimally using resources. At this time, we know very little about the unique problems experienced by lung cancer patients, and additional work in this area is mandatory to design and evaluate psychosocial intervention programs for this patient population. In particular, the lung cancer patient's social network may be especially important, and little information is available about...
this area. Development of a systematic database on the psychosocial concerns of lung cancer patients would facilitate the identification of high-risk subgroups of patients at the early phase of diagnosis and treatment. Patients with poor psychosocial adjustment could be provided with specific supportive interventions. Finally, such basic information will direct future research.

During the past decade, several approaches to the assessment of the psychosocial and rehabilitation needs of cancer patients have been developed. Some of these approaches use self-administered instruments that require only a minimum of patient time to complete (15 to 20 minutes), and they can provide detailed information for both research and clinical practice. Use of these measures may facilitate the development of a psychosocial database on lung cancer patients.

Behavioral and psychosocial interventions have been proposed for cancer patients for use within the clinical routine, for example, relaxation techniques to reduce treatment side effects. In our review of the literature, we identified several areas where a multidisciplinary management approach could increase the quality of care in lung cancer patients: prevention and management of anticipatory nausea and vomiting, as well as learned food aversions; development of techniques to encourage self-care of dyspnea and more complete relief of pain; and further evaluation and treatment of sleep disorders. There are well-established multidisciplinary programs in pain management (chronic benign pain and cancer pain) that attest to the value of this approach. In the future, multidisciplinary supportive interventions for lung cancer patients should be implemented and evaluated (Table 5).

In contrast to some of the other areas described in this review, QL research in lung cancer is at the cutting edge of scientific work. We can expect that lung cancer clinical trials will continue to provide the experimental testing ground for new research methodologies in QL research. In this actively evolving field of research, continued collaboration between clinicians and social scientists must be promoted. Just as there are known biologic prognostic factors for survival in lung cancer, eg, performance status, weight loss, cell type, and stage, patient-rated QL may prove to be a more sensitive predictor of survival.

In conclusion, our review of psychosocial issues in lung cancer identified a number of areas that need further investigation that we have summarized in Tables 4 and 5. Our review and recommendations emphasize the need for integrating the evaluation of psychosocial issues into the routine medical care of the lung cancer patient. We see this review of the psychosocial aspects of lung cancer as an initial guide for clinicians and researchers working with lung cancer patients.

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