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Chronic obstructive pulmonary disease: Behavioral assessment and treatment

Robert M. Kaplan and Andrew L. Ries

Editors' note—*Chronic obstructive pulmonary disease (COPD) is a condition that has increased throughout the world as a direct function of the number of people who smoke cigarettes. While smoking rates have decreased in the United States and many European countries in recent years (World Health Organization, 1999), this trend is not observed in many other nations. China, for example, is the world's largest producer and consumer of cigarette products. A National Prevalence Survey of 120,298 Chinese people was conducted by Yang and his colleagues (1999). The survey revealed that 34.1% of the respondents smoked, an increase of 3.4% since 1984. Smoking was more prevalent among men (63%) than women (3.8%). While 70% of the smokers knew of the link between smoking and COPD, particularly bronchitis, only a minority recognized that lung cancer (36%) and heart disease (4%) were associated with smoking. Of the nonsmokers, 53.5% were exposed to environmental tobacco smoke at least 15 min each day on more than 1 day per week.*

Two pioneering investigators in the rehabilitation of COPD patients, Bob Kaplan and Andrew Ries, describe cutting-edge research on the condition. In particular, they focus on various approaches taken to reduce the impact of COPD on patients and their families. The task Bob and Andrew have faced has been difficult because of the need to persuade COPD patients to abandon long-time behaviors, particularly smoking, while convincing them to perform new behaviors, particularly regular exercise. In addition, medical and behavioral scientists who work with the disorder have had to overcome a strong skepticism among their colleagues as to the value of rehabilitation as a treatment for patients with COPD. Only a few years ago, the schism was highlighted by a debate on the merit of pulmonary rehabilitation as an effective treatment for COPD: Albert (1997) argued that it was not effective and Celli (1997) argued that it was.

Despite the barriers they've faced, Kaplan and Ries describe progress made in synthesizing medical and behavioral procedures to treat COPD. In doing so, they not only discuss progress in the management of COPD but also provide a glimpse of what promises to be an exciting area of research to both medical and behavioral scientists.

Introduction

The term chronic obstructive pulmonary disease (COPD) is used to describe a collection of chronic disabling lung diseases. The American Thoracic Society defines COPD as

> *a disease state characterized by the presence of air flow obstruction due to chronic bronchitis or emphysema. The air flow obstruction is generally progressive, may be accompanied by airway hyperreactivity and may be partially reversible*
>
> *(American Thoracic Society, 1995)*

Chronic bronchitis, emphysema, and chronic asthma are the three diseases that contribute to the diagnosis of COPD. These diseases are similar because they all are disorders of expiration associated with obstruction of air flow out of inflated lungs. Chronic bronchitis, emphysema, and asthma differ in the nature of the airway obstruction. However, it is most common for patients to have components of more than one of these diseases.

The Obstructive Lung Diseases

Until recently, the diagnosis of emphysema was anatomic and typically made at the time of autopsy. However, newer techniques in radiology have made it possible to separate emphysema from chronic bronchitis in living people. Emphysema is caused by the loss of elastic recoil of the lung parenchyma, resulting in overinflation of the lung. These changes are typically associated with destruction of the alveolar walls, which are the walls of the small air sacs in the lung that inflate and deflate during breathing. Emphysema is a chronic condition that develops over many years and is characterized by symptoms of progressive shortness of breath on activity. The disease process is largely irreversible, and results in considerable disability for affected individuals, with high morbidity and mortality.

The consequences of chronic bronchitis are similar. However, chronic bronchitis is defined as the presence of a chronic cough and sputum production that lasts at least 3 months in 2 consecutive years. This results in chronic inflammation of the bronchi, which are the cell linings of the breathing passages. In some patients, the airways became obstructed, making breathing difficult.

Asthma is a condition associated with a reversible airway narrowing that may occur in response to stimuli such as infection, allergy, cold air, or cigarette smoke. The narrowing of the airways may be caused by a spasm of smooth muscles, inflammation, or the oversecretion of mucus. Chronic asthma occurs when the narrowing persists over the course of time. Chronic asthma and bronchitis often coexist, resulting in a diagnosis of 'asthmatic bronchitis.'

What Causes COPD?

Most of the causes and consequences of COPD are behavioral. Cigarette smoking is clearly the major risk factor for the development of these diseases. It has been estimated that 90% of cases of COPD are directly attributable to the use of cigarettes (Austin, 1976; Higgins, 1989). Compared with people who do not smoke cigarettes, current smokers are 10 times more likely to develop COPD (Higgins, 1989). The risks are approximately equal for men and women. For many years it was assumed that COPD was a disease of men. However, in recent years, as women have gained in cigarette use, rates of COPD have been escalating for females (National Heart, Lung, and Blood Institute, 1996).

Genetic factors also play an important role in development of COPD. Even among cigarette smokers, only about 15–20% develop significant COPD. Some individuals may be genetically susceptible, leaving them at much greater risk if they are exposed to cigarette smoke or other irritants. There is still debate about whether or not second-hand smoke is a significant risk factor for COPD. However, there is evidence suggesting that environmental exposures such as air pollution and exposure to dusts and fumes in the workplace may exacerbate underlying lung disease and may increase the risks of developing COPD. In addition, frequent respiratory infections in childhood increase the risk of developing COPD later in life.

Public Health Impact

COPD is a major cause of death and disability in the United States. In 1995, it was estimated that 97,262 people in the United States died of COPD (National Center for Health Statistics, 1995). This represents an age-adjusted death rate of 21 per 100,000 in the population. COPD is the fourth most common cause of death in the United States. Recent estimates suggest that there are approximately 14 million cases of chronic bronchitis reported each year and 2 million cases of emphysema (Vital and Health Statistics, Series 10, #193, 1986). In contrast to heart diseases that have been declining as a cause of death, deaths resulting from COPD increased by 38% between 1979 and 1991. Also, because COPD is an insidious disease typically diagnosed only late in the course of illness, official health statistics underestimate the burden of disease in the population.

Worldwide, COPD has ranked lower as a cause of disease burden, because smoking has been more prevalent in the industrialized countries. However, an analysis completed by the World Bank and the World Health Organization ranked disease burden in disability-adjusted life years' (DALYs) lost. They reported that COPD ranked 12th of all causes in 1990. However, the report suggests that by the year 2020, COPD will be the fifth leading cause of death worldwide (Fig. 4.1). Although smok-

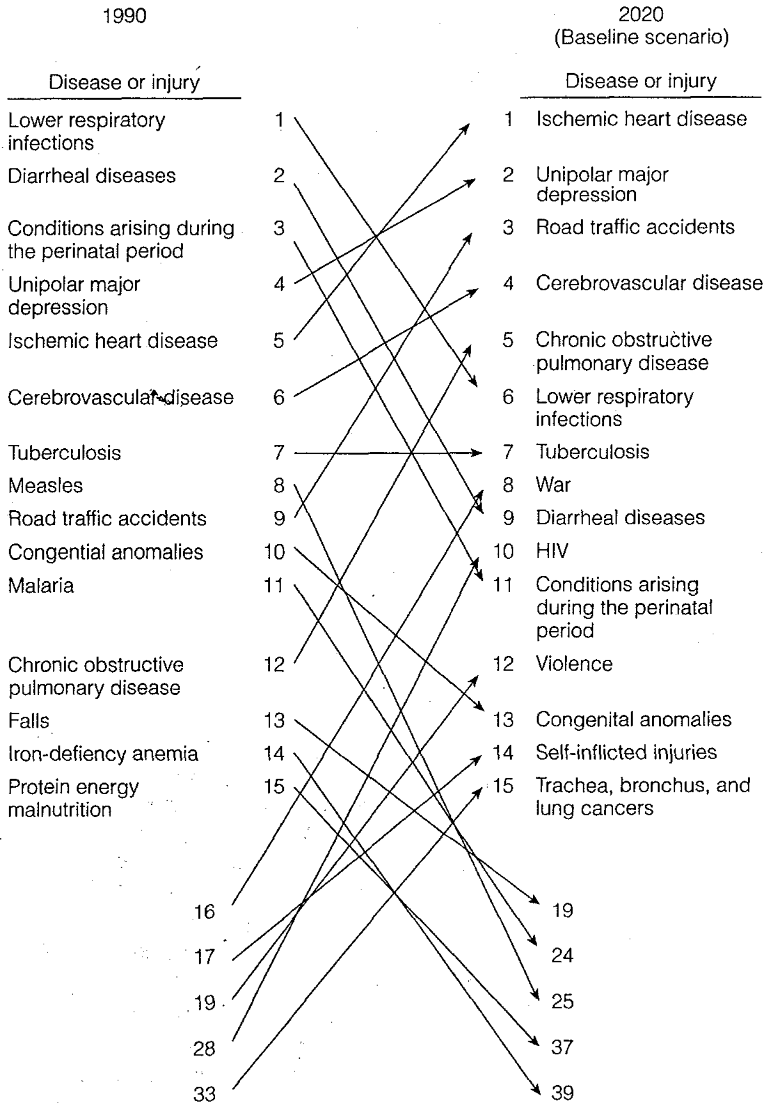

Figure 4.1

Disease burden estimated using disability-adjusted life years (DALYs), showing rank order of 15 major causes of death in the world, 1990–2020. (Reprinted with permission from Murray & Lopez, 1996.)

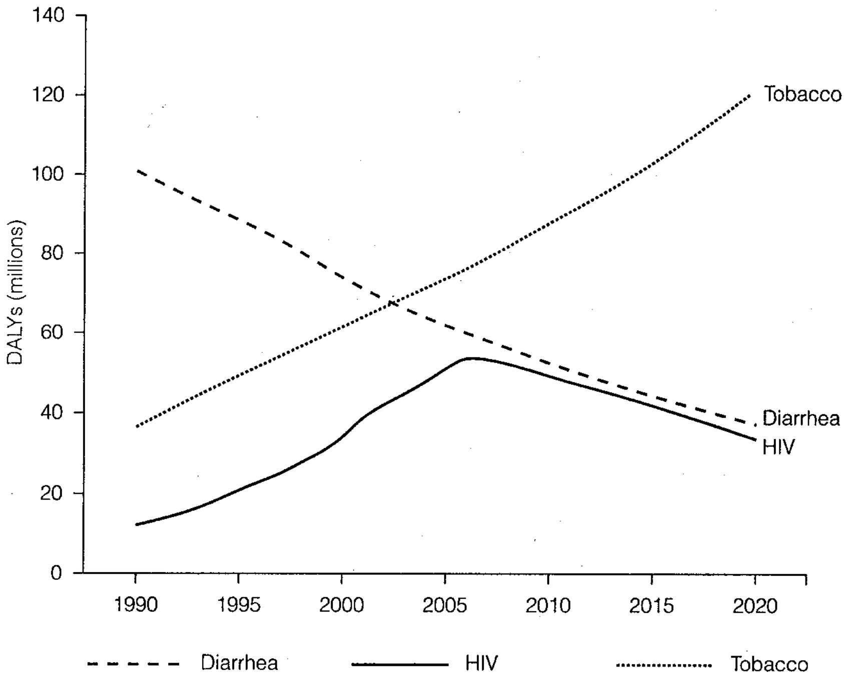

Figure 4.2

Disability adjusted life years (DALYs) for diarrhea, HIV, and tobacco use; projections for 1990–2020. (Reprinted with permission from Murray & Lopez, 1996.)

ing may have leveled off or declined in the industrialized countries, the worldwide trend is toward greater tobacco use. Figure 4.2 summarizes the WHO–World Bank estimates of DALYs lost to diarrheal disease, HIV, and tobacco between 1990 and 2020. Diarrheal disease is expected to decline steadily over this interval, while HIV is expected to peak in 2005. However, loss of life attributable to tobacco use is expected to increase steadily (Murray & Lopez, 1996).

Medical and Surgical Treatment

Medical management of COPD involves the use of medications to stabilize and/or improve airway function and symptoms, and strategies to minimize the consequences and prevent complications of the disease. Patients with COPD often use bronchodilator medicines to maximize airway size. In addition, some patients may use corticosteroids to reduce inflammation. Further, medications are sometimes used to control secretions, which is sometimes achieved by consumption of several glasses of fluid per day. Antibiotics are commonly used to control infections. Vaccinations against influenza and certain types of bacteria can prevent and reduce the risk of pneumonia. For patients with severe reductions in oxygen levels in their blood, continuous oxygen therapy has been shown to improve survival and reduce complications of the disease (Fishman, 1996).

Considerable evidence suggests that some patients may be genetically susceptible to the development of emphysema. Some of these individuals have an identified genetic abnormality that causes deficiency of a protective enzyme called α_1-antitrypsin. Recently, there has been experimentation with methods to replace the deficient protein in people affected by this condition. However, this treatment remains unproven, and the drug costs can exceed $25,000/year.

A recent development in the treatment of severe emphysema is lung volume reduction surgery (Cooper *et al.*, 1996; McKenna *et al.*, 1997). Patients with emphysema have areas of damaged lung that lose elasticity, become overinflated, and compress areas of better-functioning lung. Surgical techniques have been developed to remove these diseased sections from the lungs. However, evidence for the effectiveness of this surgery is still accumulating and the National Institutes of Health, in conjunction with the Health Care Finance Administration, is conducting a major clinical trial to evaluate the risks and benefits of these procedures.

In some patients with severe COPD, lung transplantation may be a therapeutic option. However, the expense and limited availability of donor organs means that transplantation can be made available for only a small fraction of eligible patients.

At present, medical and surgical interventions are limited because there is no cure for COPD. Behavioral interventions designed to improve functioning or to help patients cope with the illness retain an important role in contemporary care.

This chapter is divided into two major sections: the first section considers behavioral intervention and rehabilitation; the second section discusses behavioral assessments for patients with COPD.

Behavioral Intervention Studies

Kaptein (1997) reviewed randomized behavioral intervention studies involving patients with COPD: he found 15 published studies, among which 13 suggested some benefit of intervention. The outcome measures used in these studies vary considerably. Common outcome measures assess quality of life, knowledge, exercise duration, and mood. In this section intervention techniques are considered. In the next section psychosocial moderators of outcomes are reviewed.

Most behavioral intervention programs are part of comprehensive rehabilitation programs. These rehabilitation programs use multidisciplinary teams to develop individualized programs aimed at restoring patients to their highest levels of functioning. A 1994 workshop at the US National Institutes of Health defined pulmonary rehabilitation as

> *a multi-dimensional continuum of services directed to persons with pulmonary disease and their families, usually by an interdisciplinary team of specialists with a goal of achieving and maintaining the individuals maximum level of independence and functioning in the community.*
>
> *(Fishman, 1996, pp. 8–9)*

Comprehensive rehabilitation programs typically include several components. Most of the programs perform individual assessments, and offer education, instruction in respiratory and chest physiotherapy, psychological and social support, and supervised exercise training. The programs differ in the extent to which they emphasize these different components (American Thoracic Society, 1987; Guyatt *et al.*, 1987).

Hodgkin *et al.* (1993) provided a long list of methods that have established value in rehabilitation programs. The benefits suggested include reduced respiratory symptoms, reduced anxiety and depression, enhanced ability to carry out activities of daily living, increased exercise ability, improved quality of life, reduction in hospital days, and prolonged life.

These claims are difficult to validate. However, a growing literature testifies to the benefits of pulmonary rehabilitation, as documented in a series of important textbooks on pulmonary rehabilitation (Hodgkin *et al.*, 1993; Bach, 1996; Fishman, 1996). Also, a recent evidence-based guideline document reviewing the published literature has been published and supports the scientific foundation of these programs (ACCP/AACVPR, 1997).

Figure 4.3 summarizes the relationship between disability and COPD. Rehabilitation programs attempt to attend to each of these levels. The top of the figure describes the domains of pathophysiology, impairment, functional limitation, disability, and societal limitation. The bottom of the figure relates these domains to aspects of COPD. For example, the pathophysiology of COPD is obstruction of the airways. The impairment is represented by symptoms such as breathlessness, cough, or psychological depression. Functional limitations include limited abilities to exercise and perform activities of daily living. The disability associated with COPD is reflected in limitations in constructive work, deterioration of social relationships, and loss of capability of engaging in many recreational activities. Finally, the social limitation might be the inability to gain or maintain employment, the inability to use stairs or access public facilities, and so on.

PATHOPHYSIOLOGY →	IMPAIRMENT →	FUNCTIONAL LIMITATION →	DISABILITY →	SOCIETAL LIMITATION
Interruption of, or interference with, normal physiological and developmental processes or structures.	Loss and/or abnormality of cognitive, emotional, physiological, or anatomical structure or function. Impairment includes all losses or abnormalities, not just those attributable to the initial pathology and pathophysiology.	Restriction or lack of ability to perform an action in the manner, or within a range, consistent with the purpose of an organ or organ system.	Inability or limitation in performing tasks, activities, and roles to levels expected within physical and social contexts.	Restriction, attributable to social policy or barriers (structural or attitudinal), which limits fulfillment of roles, or denies access to services and opportunities, that are associated with full participation in society.

Example: Chronic Obstructive Pulmonary Disease

Adult with chronic bronchitis and emphysema.	Shortness of breath upon limited activity; easy fatigability; malnutrition; depression.	Difficulties with activities of daily living, such as eating, dressing, personal hygiene; requires supplemental oxygen during sleep and activity.	Activities of daily life require extra time and assistance; cannot do work mechanic; cannot do hobbies and recreational activities; not independent with family and peers.	Difficulties in finding employment; lack of involvement in social activities; health insurer limits home care; limited access to recreational activies.

Figure 4.3

Relationship between disability and COPD. (Reprinted with permission from Fishman, 1996.)

History

Rehabilitation has always been part of medical care. However, developments in 18th century Europe may have set the stage for contemporary rehabilitation programs. With the French Revolution in 1789 came a declaration of rights of man and the citizen. The declaration proclaimed that unfortunate citizens should be supported by society and that society should make education available to everyone. Another 18th century development was the spread of tuberculosis during the industrial revolution; epidemic-proportion tuberculosis may have resulted from rapid urbanization. Treatments involved separating the infected individuals and relocating them to sanatoriums with clean, dry air. Relaxation was a part of the therapy in the sanitoria until the introduction of antibiotics changed the treatment of the disease (van den Broek, 1995).

San Diego Programs

Over the last few decades, we have conducted several studies to evaluate behavioral and rehabilitation interventions for patients with COPD. Our first experimental study was published in 1984. This was not an evaluation of comprehensive rehabilitation. Instead, the study focused on behavioral interventions designed to increase exercise. At the time, we were persuaded that exercise was the key component of rehabilitation for patients with COPD. A variety of earlier studies had shown benefits of exercise interventions in small or non-controlled studies (Bell & Jensen, 1977; McGavin *et al.*, 1977; Mertens *et al.*, 1978; Ambrosino *et al.*, 1981; Belman & Wasserman, 1981). Each of these studies demonstrated some benefit of physical activity, but the studies differed greatly in the percentage of patients followed for longer than 3 months and the methods of outcome assessment.

The issue addressed in our original study was not whether exercise benefits patients, but rather how to enhance regular physical activity among patients with COPD. Many patients with COPD experience shortness of breath and discomfort during physical activity. Thus, behavior modification and cognitive modification were used to train patients to cope with the discomfort associated with regular physical activity. The study randomly assigned 78 COPD patients to one of five experimental groups. Three of the five groups were given various behavioral interventions. One group received traditional behaviour modification that emphasized goal setting, analysis of reinforcers, and behavior contracts. A second group received cognitive modification and emphasized self-taught and positive self-statements. A third cognitive–behavior modification group received an intervention that used the technology of behavior modification to modify patient self-statements.

Each of these interventions was designed to enhance regular physical activity during everyday activities. Sessions were conducted in the patient's home and the interventions were designed to promote activity in the patient's usual home environment. The study included two control groups: one group received attention but did not have behaviorally based sessions; the second control received no treatment at all.

Patients in this study were evaluated at baseline, 3 months, 6 months, 12 months, and 18 months. Figure 4.4 shows changes in self-reported physical activity during the first three months for the five groups. The figure suggests that the cognitive–behavior modification and cognitive modification groups increased their physical activity significantly more than the behavior modification group or the control groups.

All the participants were given treadmill endurance tests by a technician blinded to the experimental conditions. Changes in self-reported

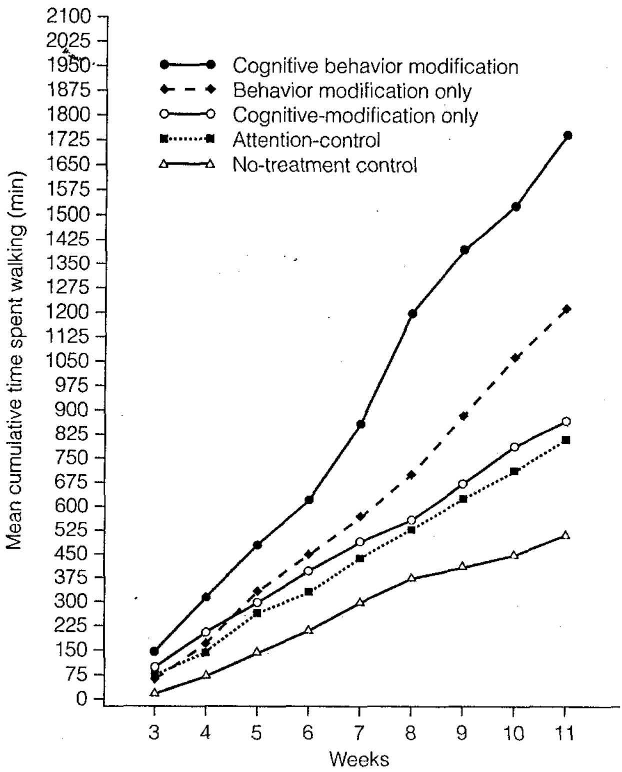

Figure 4.4

Cumulative self-reported walking in five groups. The three behavior modification groups exceed the two control groups. (Reprinted with permission from Atkins *et al.*, 1984.)

exercise were validated by improvements in laboratory exercise endurance tests taken 1 month following the end of treatment (Fig. 4.5).

In addition to changes in exercise endurance, we also measured quality of life outcomes using a general assessment procedure known as the quality of well-being scale (QWB). After 3 months, differences between the small treatment groups began to disappear. However, averaging over three experimental groups and two control groups, differences between treated and untreated patients remained. These are shown in Fig. 4.6. Those in treated groups declined slightly over the course of 18 months, while those randomly assigned to control conditions showed a significant reduction in the quality of life over 18 months.

The study also included an extensive battery of pulmonary function tests. Consistent with most other studies in the literature, pulmonary function did not improve or decline as a function of treatment (Atkins *et al.*, 1984).

Several noncontrolled studies have also supported the use of cognitive behavioral interventions. For example, Lisansky & Clough (1996) offered an 8-week cognitive behavioral self-help education program to eight patients with COPD. They found significant improvements for the

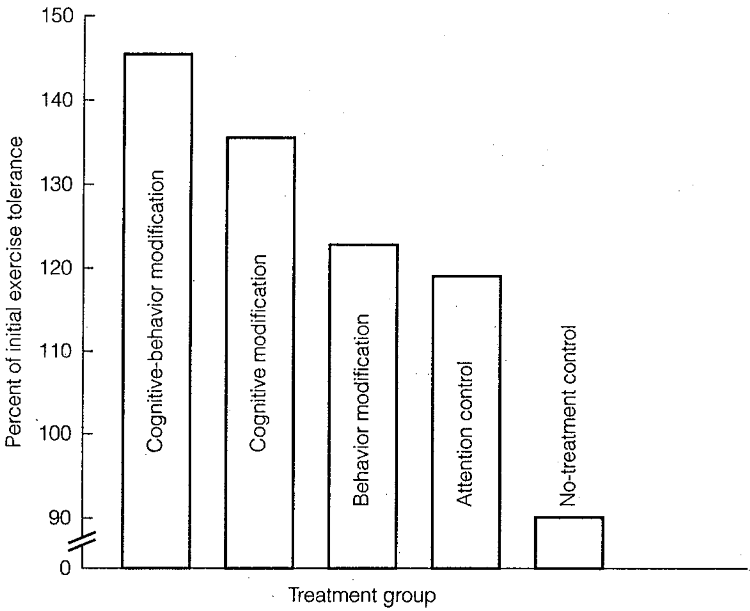

Figure 4.5

Percent of initial exercise endurance for five groups at 3 months. (From Atkins *et al.*, 1984.)

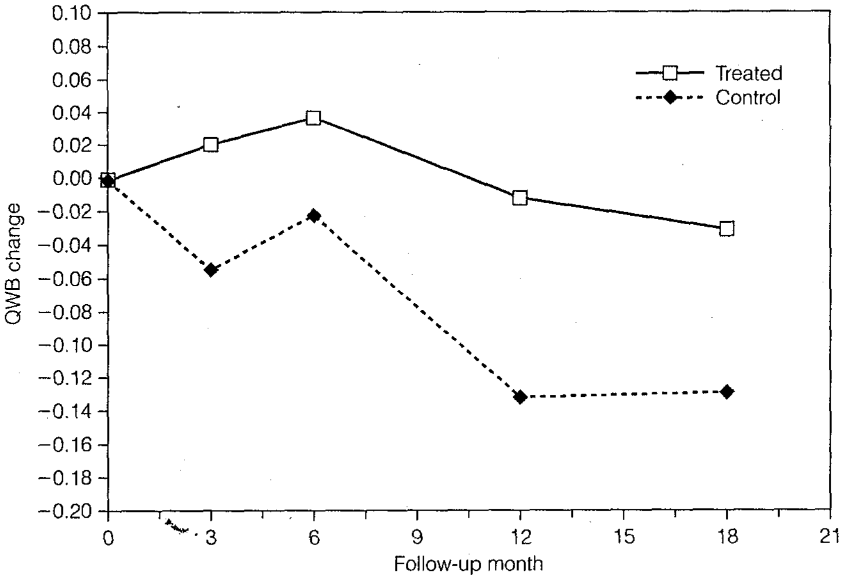

Figure 4.6

Change in quality of well-being (QWB) for three treatment groups (combined into 'treated' line) and two control groups (combined into 'control' line). (From Toevs *et al.*, 1984.)

psychosocial and total scores of the sickness impact profile. Eiser *et al.* (1997) compared cognitive behavioral psychotherapy to a control group that included lung function, testing, and walking. Their psychotherapy and controlled interventions lasted 6 weeks. Those who completed the behavioral program showed sustained improvement in exercise tolerance but did not improve on measures of anxiety or depression.

Because of the complexity of COPD, psychological intervention independent of a comprehensive program is usually not advisable. Typically, psychological and behavioral treatments are components of a comprehensive rehabilitation program. Pulmonary rehabilitation is now an established therapy for people with advanced COPD. A variety of studies have demonstrated that rehabilitation can alleviate symptoms, improve function, and reduce medical care costs (Toevs *et al.*, 1984; Bach, 1996; Fishman, 1996; ACCP/AACVPR, 1997). Pulmonary rehabilitation usually requires a multidisciplinary team of experts in behavioral science, respiratory and chest physiotherapy, medicine, and exercise science.

We have conducted several studies designed to evaluate outcomes of pulmonary rehabilitation. In one study, 119 outpatients with stable but advanced COPD were randomly assigned to pulmonary rehabilitation or to a control condition. The pulmonary rehabilitation program lasted 8 weeks and included twelve 4-hour sessions that integrated education, physical and respiratory care instruction, psychosocial support, and supervised exercise training. In addition, participants attended monthly reinforcing sessions for 1 year. The control group emphasized education alone. Control participants attended two 4-hour sessions that included videotapes, lectures, and discussions about lung diseases. However, those in the control group did not receive individualized instruction or training in exercise.

A variety of physiological and psychological measures were used to evaluate the program, including measures of lung function, maximum exercise tolerance and endurance, gas exchange, symptoms of perceived breathlessness, physical fatigue during exercise, shortness of breath, self-efficacy for walking, depression, medical care utilization, and quality of life. Prior to the intervention, the treatment and control groups were equivalent on a wide range of physiological and psychosocial measures. Following the treatment, those in the pulmonary rehabilitation program (compared with education controls) showed significant improvements in exercise endurance, maximum exercise tolerance, symptoms of perceived breathlessness, muscle fatigue during exercise, reported shortness of breath with daily activities, and self-efficacy for walking. Some of these benefits gradually declined over the course of 1–2 years. However, the benefits for perceived muscle fatigue and breathlessness persisted for at least 6 months and the benefits for maximum treadmill workload and exercise endurance remained significant for 1 year. Some of the psychological benefits persisted for longer. For example, differences in self-efficacy for walking remained statistically significant for up to 18 months, while differences in rating of perceived breathlessness during exercise persisted for 24 months.

Outcomes for treadmill endurance, perceived breathlessness, and muscle fatigue are summarized in Fig. 4.7. Consistent with other rehabilitation studies, differences between rehabilitation and educational control groups on physiological measures of lung function were not statistically significant at any follow-up (Ries *et al.*, 1995).

Psychosocial Mediators of Outcome

Several chapters in this book concern important mediators of outcome in COPD, including dyspnea (see Chapter 5), compliance (Chapter 8), quality of life (Chapter 9), and other issues (Chapter 14). These and a variety of other psychosocial variables are important for understanding outcomes for patients with COPD. In the following sections we review several psychosocial variables that may be of importance for patients with COPD. We begin with variables that may be related to survival and

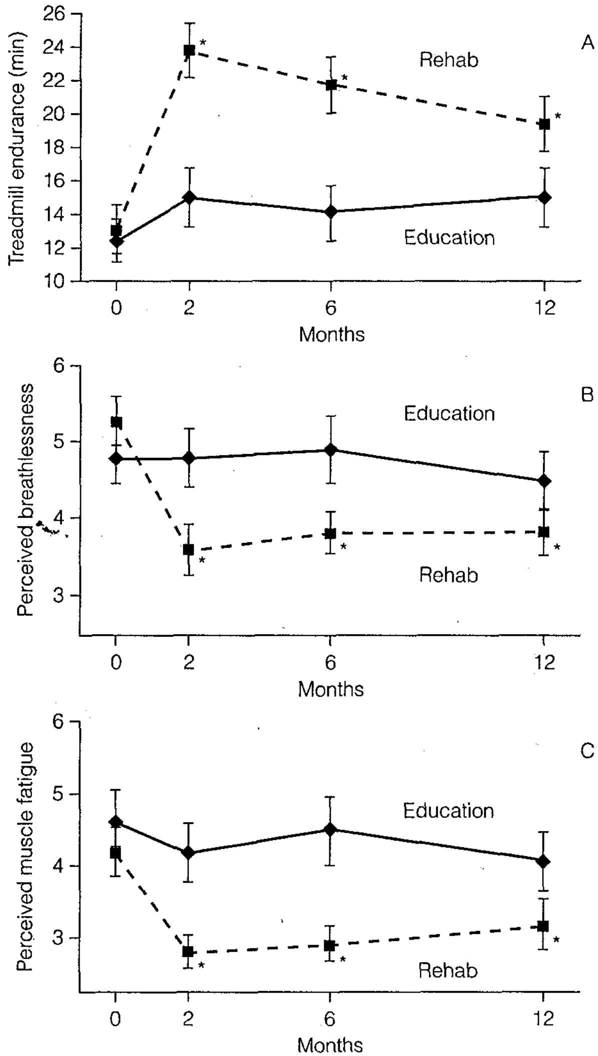

Figure 4.7

Results of treadmill endurance exercise tests for patients in the rehabilitation (Rehab) and education groups at baseline and for 12 months of follow-up. A, exercise endurance time; B, perceived breathlessness rating at the end of exercise; C, perceived muscle fatigue. Asterisks indicate $p < 0.05$ for within-group change from baseline; values and error bars represent the mean ± SE (From Ries *et al.*, 1995.)

proceed with discussion of variables that may mediate treatment outcomes.

Psychosocial Variables and Survival

We have found psychosocial variables to be related to survival for patients with COPD. These are quality of life, social support, and self-efficacy.

Quality of Life

Quality of life is now recognized as an important outcome in studies of medical care. The measurement of quality of life in lung disease is reviewed elsewhere in Chapter 9. In our studies, we have favored quality of life measures that can be used in cost-effectiveness analysis. Measures that incorporate morbidity and mortality in the same scale have the advantage of avoiding survivor and healthy subject biases inherent in other measures. In studies of patients with COPD, both disease-specific and general measures have been applied.

Disease-specific measures usually focus on shortness of breath (Eakin *et al.*, 1993, 1998; Eakin & Glasgow, 1996). Dyspnea is the subjective sensation of difficult or labored breathing. It is one of the most common symptoms of patients with COPD. Various authors have described a dyspnea–panic cycle in which the experience of breathlessness leads to anxiety, creates muscle tension, and results in increased dyspnea and panic (Kaplan *et al.*, 1985).

In addition to disease-specific measures that emphasize shortness of breath, general measures are used to provide a more comprehensive assessment of health status and well-being; one example is a general health status index known as the quality of well-being scale (QWB). The QWB is a utility weighted measure that classifies patients according to observed levels of functioning. These levels are represented by scales of mobility, physical activity, and social activity. In addition to classification according to observable function, individuals are also classified by their chief symptom or problem. On any particular day, nearly 80% of the general population is at an optimum level of function. However, fewer than half of the population experience no symptoms (Kaplan *et al.*, 1976). Symptoms or problems may be severe, such as serious chest pain, or minor, such as taking medications or a prescribed diet for health reasons. Preferences or values are used to map function states and symptoms onto a 'quality continuum ranging between 0.0 (for death) and 1.0 (for optimum function).' The quality-adjusted life year (QALY) is defined as the equivalent of a completely well year of life or a year of life free of any symptoms, problems, or health-related disabilities. The QWB scale has been validated for patients with COPD (Kaplan *et al.*, 1984) as well as for patients with other lung diseases (Orenstein *et al.*, 1989).

Quality of life is an important outcome for patients with COPD. However, it is also an important predictor of outcomes. One study predicted survival among 74 patients selected for lung transplantation (Squier *et al.*, 1995). While on a waiting list to receive lung transplant, patients completed the QWB along with a variety of measures of lung function. The Beck Depression Inventory was also administered. These 74 patients were followed prospectively. Forty-nine of the patients eventually received a lung transplantation. Of the original 74 patients, 24 died: 13 who had received lung transplant and 11 who were still on the waiting list. Survival analysis was used to determine predictors of survival.

These analyses demonstrated that the QWB was the best prospective predictor of survival. Interestingly, whether or not the patients received lung transplant did not significantly predict survival. Figure 4.8 summarizes these results. The figure shows that a higher proportion of patients who obtained QWB scores above the median survived compared with patients whose initial QWB scores were below the median (relative risk = 0.45, $p < 0.05$). These findings suggest that quality of life may be an important predictor of survival for patients with severe lung disease. It

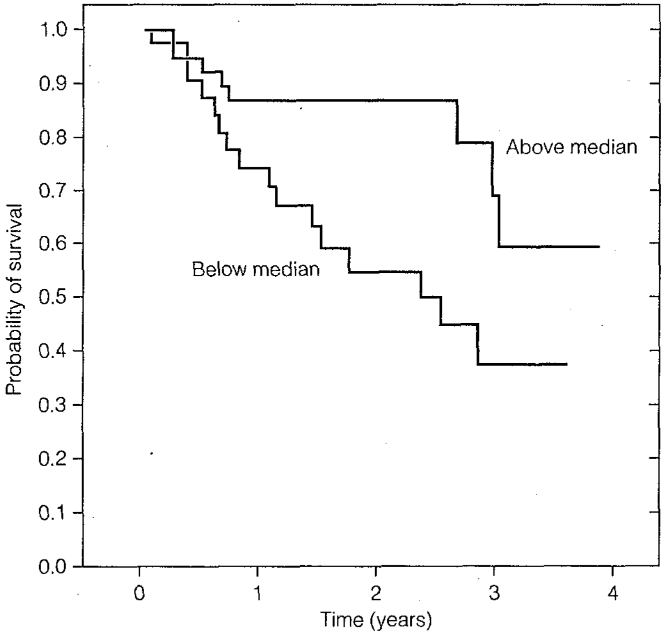

Figure 4.8

Kaplan–Meier proportional estimate survival curves: Above median quality of well-being (QWB) scores versus Below median QWB scores. (From Squier *et al.*, 1995.)

is important to emphasize that the patients in this analysis included those with other lung diseases such as cystic fibrosis and vascular lung disease in addition to those with COPD (Squire *et al.*, 1995).

Social Support

Several papers have argued that older adults with COPD often have difficulty with social relationships. For example, Leidy & Traver (1996) reported that family members of patients with COPD are often dissatisfied with their social relationships with the patient. In particular, they disliked disruptions of free-time activity. A variety of other studies have documented the importance of psychosocial adjustment for patients with COPD (Leidy & Traver, 1995; Lewis & Bell, 1995; Büchi *et al.*, 1997).

One factor that may be particularly important is social support. A growing literature suggests that supportive social relationships are associated with positive health outcomes (Pierce *et al.*, 1996). Most studies define social support as the number of persons in a social network. However, recent conceptualizations go beyond network size and consider quality of social relationships. Thus, in addition to quantity, quality is also important. In order to evaluate the role of social support in patients with COPD, we used measures developed by Sarason *et al.* (1983). These investigators developed a social support questionnaire that measures the number of persons in the social network (SSQ-N) and the self-perception of satisfaction with available support (SSQ-S). In one investigation, we considered the relationship between social support and survival for patients with COPD. The study found significant correlations between both the SSQ-N and SSQ-S with a variety of measures, including exercise tolerance, shortness of breath, and lung function. Among the patients with COPD followed over the course of 6 years, there were 68 survivors and 42 nonsurvivors. Survival analysis was conducted using the Cox proportional hazard model. The analysis demonstrated that SSQ-S (but not SSQ-N) was related to longer survival (Hazard ratio = 0.79, 95% CI = 0.63–0.99). In other words, those who were satisfied with their social support experienced a 21% increase in the chance of survival over 6 year (Grodner *et al.*, 1996).

Survival functions for males and females are shown separately in Figs 4.9 and 4.10. For males, there was a trend for improved survival for those who had high SSQ-S scores; however, the differences were nonsignificant. For females, there was a significant benefit of social support satisfaction: women with low social support satisfaction were significantly more likely to die within 6 years compared with women who had high satisfaction with their social relationships (Grodner *et al.*, 1996). Other studies have also suggested a relationship between social support and survival for women but not men. For instance, the Tecumseh Community Health Study demonstrated a relationship between social support and survival among women (House *et al.*, 1982). The Framingham Heart

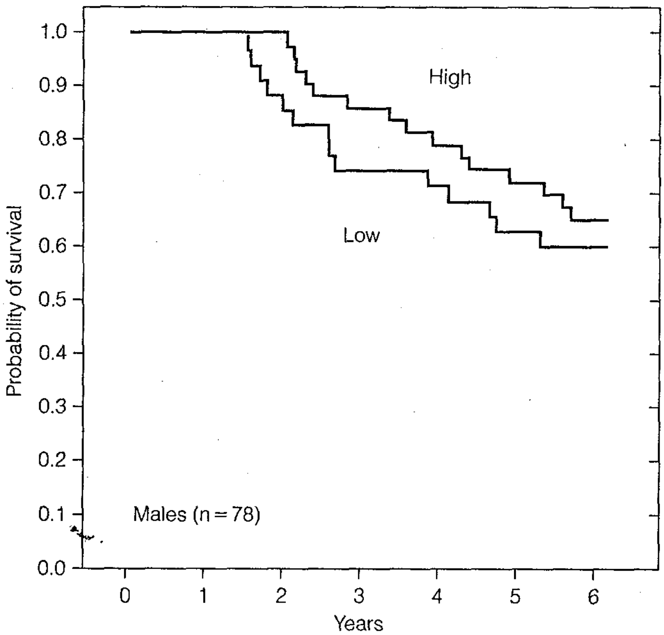

Figure 4.9

Survival of 78 males for high versus low social support satisfaction. (Reprinted from Grodner *et al.*, 1996.)

Study reported that women (but not men) with nonsupportive spouses were more likely to be victims of heart disease (Haynes & Feinleib, 1980).

Self-Efficacy

A third variable that may predict survival for patients with COPD is self-efficacy expectation. Self-efficacy expectancies are defined as expectations that a particular behavior can be executed or completed (Bandura, 1977). A substantial literature suggests that self-efficacy expectations play an important role in the execution and maintenance of complex behaviors (Schwarzer, 1992). We have performed several studies demonstrating that specific rather than generalized efficacy expectations mediate changes in patients with COPD (Kaplan *et al.*, 1994).

To measure self-efficacy, we adapted a self-efficacy scale that was originally developed to measure expectations for completing activities that imposed burden for patients who had experienced uncomplicated myocardial infarction (Ewart *et al.*, 1983). For studies of patients with COPD the self-efficacy questionnaire was modified to more accurately

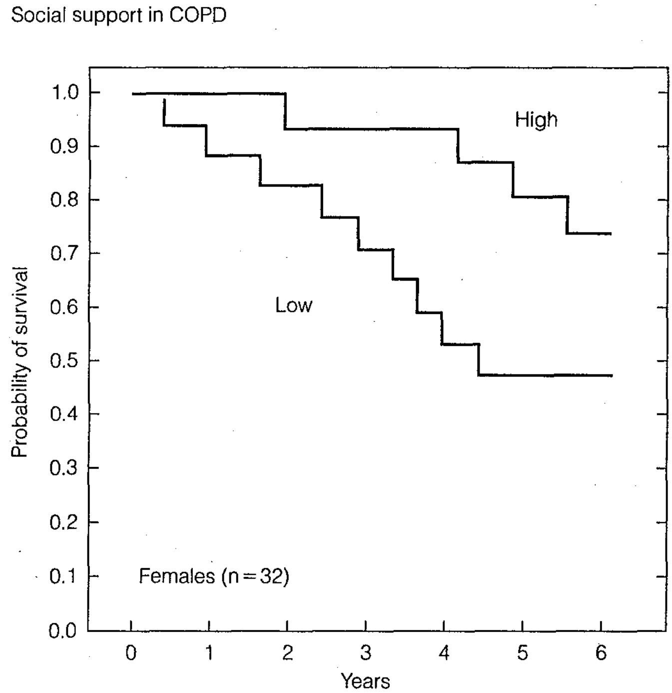

Figure 4.10

Survival of 32 females for high versus low social support satisfaction. (From Grodner *et al.*, 1996.)

represent disabilities associated with this condition. In a series of studies, we demonstrated the validity of the self-efficacy construct by showing systematic correlations with lung function and exercise variables. For example, simple self-efficacy ratings for exercise are systematically related to measures of pulmonary function (Fig. 4.11). The efficacy for walking measures were also associated with diffusion capacity (Fig. 4.12) and exercise tolerance. For example, in the study of exercise tolerance, patients by lowest, middle, or highest tertile of each efficacy category are related to $Vo_{2\,max}$ as assessed in treadmill tests by blind observers (Toshima *et al.*, 1992b).

Self-efficacy ratings are simple to obtain. There has been a predominant tradition in medical science to disregard patient self-reports. Often, self-reports are regarded as unreliable and of low validity. These amateur reports provided by patients are typically devalued in relation to objective tests. However, self-evaluated health status tends to be a good prospective predictor of survival (Mossey & Shapiro, 1982). In one study, we

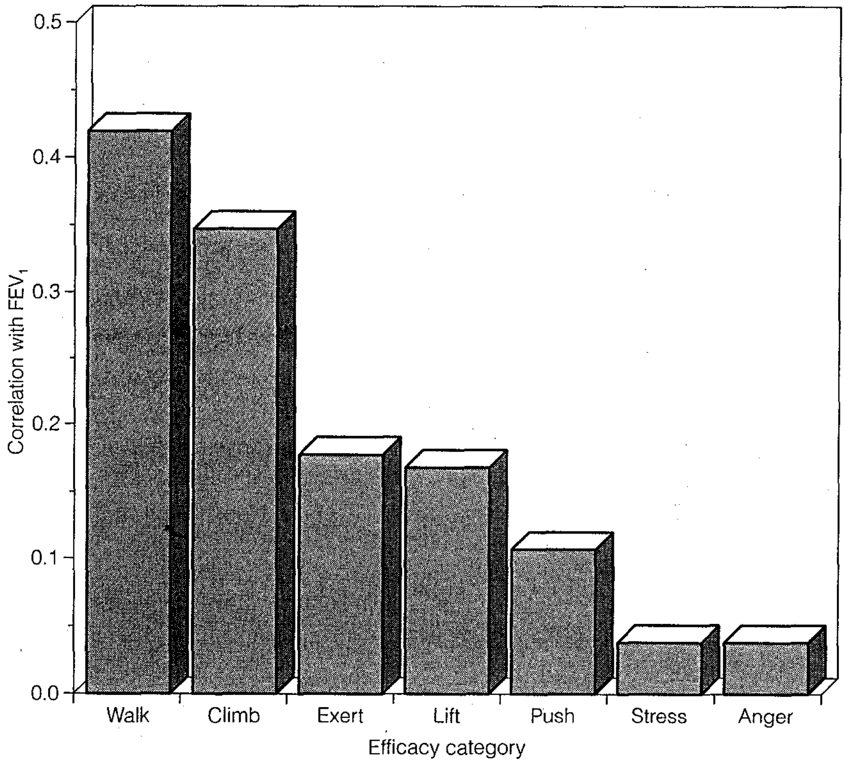

Figure 4.11

Correlations between categories of self-efficacy and FEV_1. Exercise efficacy expectations are more highly correlated with pulmonary function. (Adapted from Toshima *et al.*, 1992b.)

compared the predictive value of simple self-efficacy ratings for exercise against a series of physiological variables. In an earlier study, 28 physiological indicators of disease severity for COPD were factor analyzed. The analysis demonstrated that physiological measurements were highly redundant and are best summarized by four constructs: pulmonary function, diffusing capacity, maximum exercise tolerance, and arterial oxygen level (Ries *et al.*, 1991).

Using data from our prospective study, we developed a predictive model that included these four physiological parameters along with self-efficacy expectations. These variables were assessed at baseline and patients were followed prospectively for 5 years. Death certificates were obtained for all deceased patients. The analysis included 75 patients who survived for 5 years and 33 who died. In a univariate analysis,

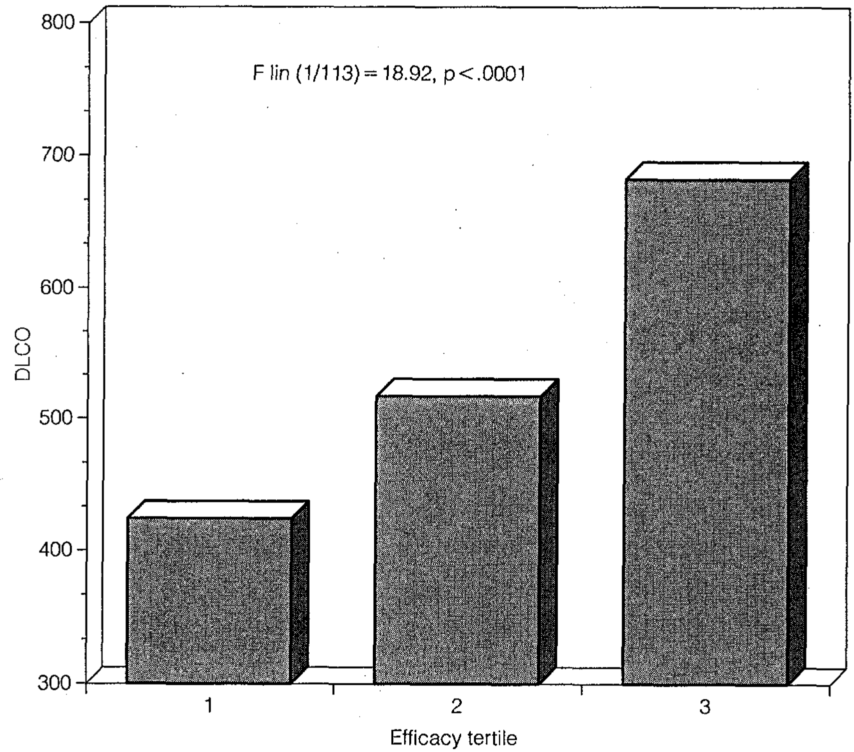

Figure 4.12

Relationship between diffusing capacity (DLCO) and tertile of self-efficacy. (Adapted from Toshima *et al.*, 1992b.)

self-efficacy for walking was a significant predictor of survival ($\chi^2 = 9.01$; d.f. = 1; $p < 0.01$) (Fig. 4.13). The analysis also showed that three other variables were also significant predictors of mortality (FEV_1, $Vo_{2\,max}$, and DLCO). Arterial blood oxygen was not a significant predictor of survival. Multivariate analysis was used to estimate the effects of physiological variables after self-efficacy had been removed. In this analysis, only pulmonary function (FEV_1) added significant information beyond self-efficacy.

These analyses are interesting because they suggest that a simple self-rating of efficacy expectation significantly predicts survival for patients with COPD. The finding compliments other observational studies that have shown that simple patient ratings provide a significant amount of information. It could be argued that the self-efficacy ratings are unimportant because they are only proxies for disease severity. On the other

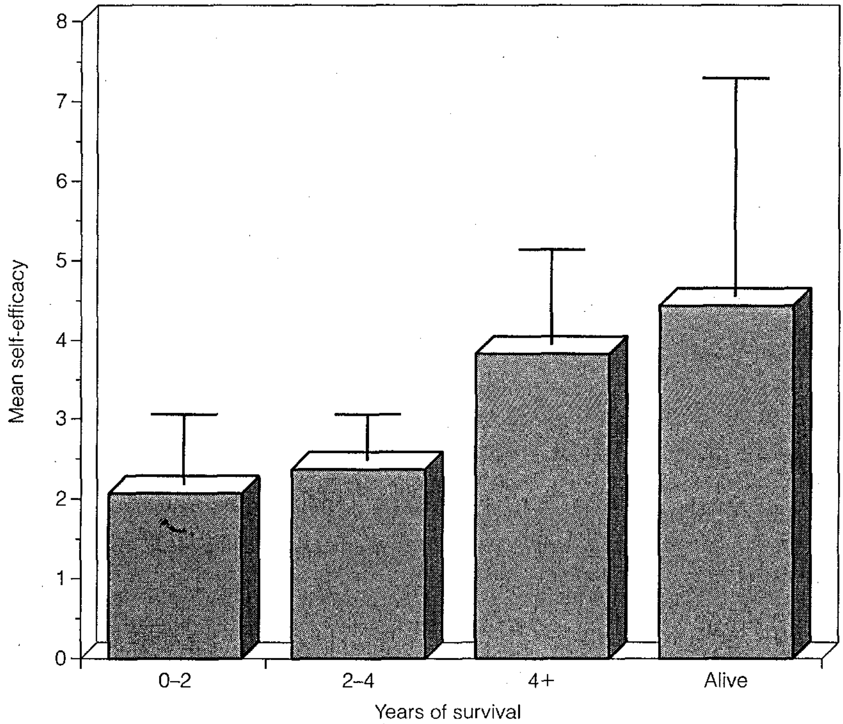

Figure 4.13
Mean self-efficacy for walking by years of survival. (From Kaplan *et al.*, 1994.)

hand, these simple ratings, which literally take a few seconds to assess, compete favorably with expensive laboratory tests when used as predictors of survival. Other studies have shown that simple self-reports provide significant information about survival. In one review, Idler & Kasl (1995) found that simple self-reports have predicted survival in 11 separate studies. These analyses typically use statistical control for other risk factors. Clearly, efficacy expectations are driven by severity of illness. Nevertheless, these findings support the validity of simple self-reports for predicting survival.

Mediating Variables

Several variables may help explain the relationship between behavioral intervention and health outcome; these include dyspnea, compliance and depression.

Dyspnea

Dyspnea, the clinical term for shortness of breath, is defined as the subjective sensation of difficult or labored breathing. Dyspnea is one of the most common and disabling symptoms of people with COPD (Eakin *et al.*, 1993). The sensation of labored breathing can be extremely distressing and may be perceived as life threatening in addition to limiting the function and quality of life of people with COPD. In addition to COPD, dyspnea is common in other medical conditions (e.g., cardiac disease, obesity, neuromuscular disorders affecting the respiratory system).

The sensation of dyspnea is often accompanied by fear and anxiety (Eakin *et al.*, 1993). Several authors have described a dyspnea–panic cycle in which the experience of breathlessness leads to anxiety, which creates muscle tension, resulting, in turn, in increased dyspnea and panic (Dudley *et al.*, 1980). The distress caused by dyspnea can become part of a vicious cycle, leading to fear of future shortness of breath. This may cause patients with COPD to slowly decrease their activity level. In turn, patients become deconditioned, leading to greatly limited independent functioning and quality of life (Ries, 1990).

One hypothesis is that treatment that focuses on dyspnea will result in improved functional outcomes. To address this hypothesis, we evaluated a treatment program centered on training patients to cope with this one symptom. Eighty-nine patients with COPD were randomly assigned to either 6 weeks of treatment or to a general health education program. The treatment was specifically designed to help patients cope with dyspnea. Patients assigned to the treatment protocol were given instruction in progressive muscle relaxation, breathing exercises, pacing, self-talk, and panic control.

To evaluate the effectiveness of the treatment, all patients were evaluated by a 6-min walk test, the QWB, and a series of psychological measures. In addition, they completed six different measures of dyspnea. The measures were administered before the treatment, after the treatment, and 6 months following the intervention.

Following the 6-week treatment, there were no differences between the treatment and control groups on any outcome measure. At the 6-month follow-up, there was a significant difference for only one variable: the dyspnea index (Mahler & Wells, 1988). The results of this study suggest that management of dyspnea alone is not enough to produce significant outcome changes for patients with COPD. Although the program may have some mild effect on the symptom of dyspnea, it did not have an effect on exercise tolerance, quality of life, or any measure of anxiety or depression. As a result of this experience, we now believe that programs must include other behavioral components. In particular, we believe that exercise training is probably one of the most important components of any program (Sassi-Dambron *et al.*, 1994).

Compliance

The rehabilitation programs prescribed for patients with COPD are often difficult to follow. Typically, patients are asked to participate in education, physical and respiratory therapy, and exercise training. Several of our studies have focused on the exercise training component. This is of particular interest because exercise causes discomfort and produces anxiety for many patients. In one study, patients assigned to a rehabilitation program participated in 12 exercise training sessions. During these sessions, the patients walked on a treadmill and performed upper body exercises. The speed of the treadmill was individually determined on the basis of a maximum exercise tolerance test. Patients were individually instructed in translating the treadmill walk into a free-walking regimen that included the number of minutes to be walked and the steps per minute. The patients were then asked to implement this prescription in their daily routines. Specifically, they were asked to walk twice daily at the prescribed pace and duration for the 2 months' duration of the program. In addition, they were asked to keep a daily log of the time and distance they had walked for at least 8 weeks.

Each week the logs were reviewed and the average minutes per day walked was calculated for each patient by dividing the total number of recorded minutes walked during the 8-week period by the total number of days that the patient could have walked. To determine whether compliance was related to outcome, an exercise endurance walk was performed prior to the program and after 12 weeks. During this test, the patients were urged to walk on the treadmill for as long as possible, up to a maximum of 20 min at the target work load, and an additional 10 min at a higher work load.

The results of the study showed there was a dose–response relationship between compliance with walking prescriptions and improvements in exercise endurance. Thus, compliance with the exercise program was a significant predictor of improved exercise endurance. A linear equation was fit to the data. This analysis suggested that each 0.35 min change in compliance resulted in a 1-min improvement in exercise endurance (Fig. 4.14). A variety of analyses were conducted to determine if other variables explained these improvements. The relationship was not diminished by statistical controls for initial levels of disease severity or for any other patient characteristic. Thus, it appears that volitional patient behavior is an important component of improvements in exercise endurance for patients undergoing pulmonary rehabilitation; i.e., patients' choices to comply with daily exercise prescriptions may have a significant effect upon health outcome (Eakin *et al.*, 1992).

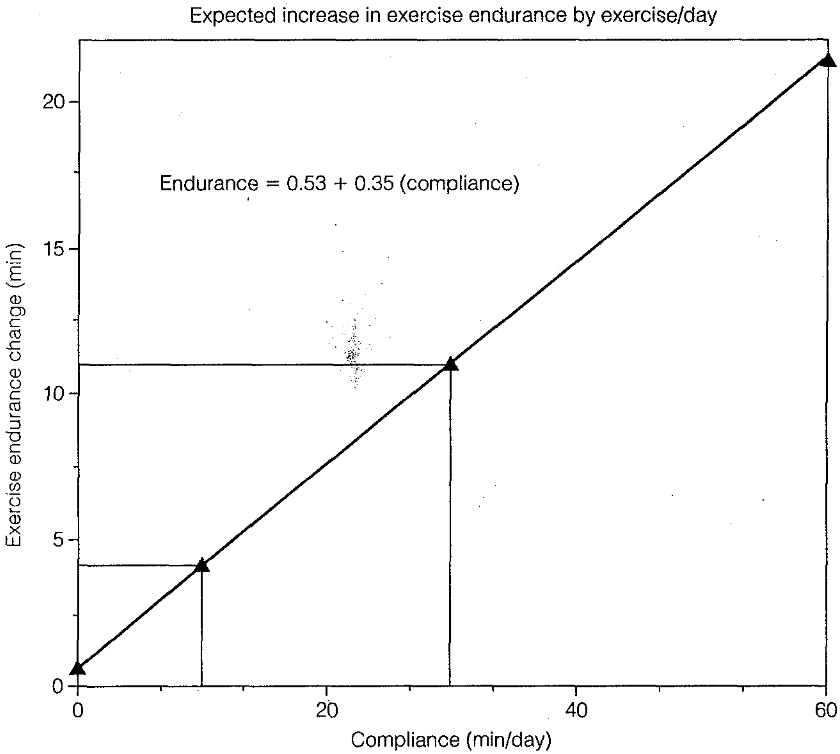

Figure 4.14

Regression of compliance on exercise. Each 0.35 unit change in compliance resulted in a 1-min change in exercise endurance. (From Eakin *et al.*, 1992.)

Depression

A variety of studies demonstrate that patients with chronic illness experience more psychological distress than nondisabled populations. This has clearly been shown in a variety of studies involving patients with COPD (Dudley *et al.*, 1980; Maillé *et al.*, 1994; Herbert & Gregor, 1997; Tu *et al.*, 1997). One explanation of the high levels of depression in patients with COPD is that disability prevents patients from obtaining the reinforcers of everyday life. Abramson *et al.* (1989) defined hopeless depression as an individual expectation that highly desired outcomes will not occur or highly aversive outcomes will. This definition emphasizes that depression will result when people have no control over important events. If this theory is correct, then behavioral interventions that give patients more control and improve their activities of daily living might result in reduced depression.

This hypothesis was evaluated in our experimental trial on rehabilitation. Depression was measured using the CES-D scale. This is a 20-item scale that assesses dimensions of depressed mood, feelings of guilt and worthlessness, appetite loss, sleep disturbance, and energy level (Weissman *et al.*, 1977).

Although patients randomly assigned to rehabilitation improved on functional outcomes, they did not demonstrate lower levels of depression. Comparisons between the education and rehabilitation groups were nonsignificant. Within each treatment group, however, other comparisons were made. The patients were subdivided into two groups based on their changes in depression. One group included those who had increased depression (50 patients) and the other group included those who had a decrease between the baseline and the post-treatment follow-up (52 patients). The data were reanalyzed as a function of treatment circumstances, with depression (increased versus decreased) serving as a categorical independent variable. In the rehabilitation group, the patients who had decreases in depression levels showed a significant increase in exercise endurance performance. For those in the education group, increasing or decreasing depression was unrelated to improved exercise endurance (Fig. 4.15).

Another series of analyses separated the patients who were depressed at baseline ($n = 25$) and those who were not depressed ($n = 74$). The frequency of depression at baseline was approximately equal in the rehabilitation and the education groups. Depression was defined as a CES-D score greater than or equal to 18. Eight patients had to be eliminated from the analysis because of missing data. The analyses demonstrated that, for some variables, there was a differential response to treatment as a function of baseline depression. This was most apparent for changes in exercise tolerance ($Vo_{2\,max}$). For changes in this variable, there were no differences between the education and rehabilitation programs for those who initially had low depression scores. However, for patients who were initially depressed and assigned to the rehabilitation program, there were significant improvements in exercise tolerance; i.e., the rehabilitation program was particularly useful for patients who were initially depressed (Fig. 4.16). This finding is particularly interesting since several authors have suggested that depressed patients be screened out of rehabilitation programs. These data suggest that depressed patients may, indeed, gain even more from the rehabilitation interventions.

Depression is likely to be a comorbidity for patients with any chronic illness. Although it is difficult to make comparisons across studies, it appears that about 40% of patients with COPD experience depression (Isoaho *et al.*, 1995). In our work, 29% of patients reported clinically significant levels of depression at their initial assessment, as determined by

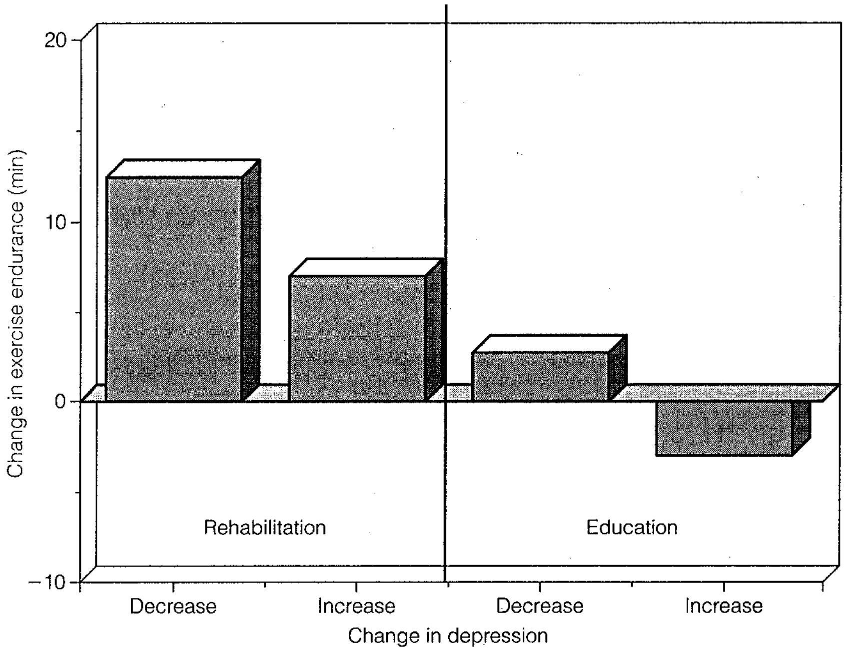

Figure 4.15

Changes in exercise endurance among rehabilitation and education patients who increased or decreased in depression. (From Toshima *et al.*, 1992a.)

CES-D scores greater than 18. The measurement of depression for patients with COPD is difficult because most assessments are based on the general population. For example, items on the CES-D and other depression measures assess decreased sleep, poor appetite, decreased energy, and so on. These are often symptomatic experiences of lung disease. It is not uncommon for patients with COPD to have trouble sleeping or decreased energy because of dyspnea. Further, many patients with COPD report decreased appetite because of the discomfort associated with a full stomach pressing on the diaphragm. Therefore, scores on depression measures may not accurately reflect the level of clinical depression in patients suffering from chronic diseases such as COPD. We do not yet understand whether responses to some items represent the lung disease or depression, so it is impossible to determine how many patients who report depression-like symptoms actually have a major affective disorder. Considerably more work on the importance of depression and the role of the behavioral intervention is needed (Toshima *et al.*, 1992a).

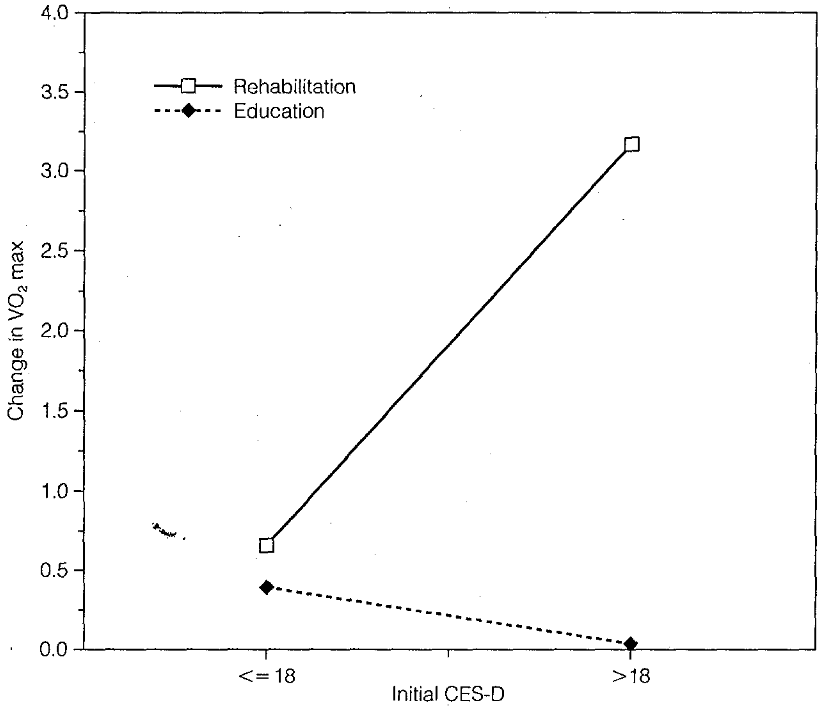

Figure 4.16

Changes in $VO_{2\,max}$ as a function of initial depression for rehabilitation and education patients. (From Toshima *et al.*, 1992a.)

Conclusion and Future Directions

Chronic obstructive pulmonary disease has received relatively little attention from behavioral scientists. Several important challenges await investigators interested in this field. First, behavioral risk factors for COPD have been well studied, but deserve ongoing attention. Changes in the prevalence of tobacco use might effect future epidemic patterns. Further, environmental exposures and unique interactions between genotypes and lifestyle might define future populations at risk.

A second important area of investigation involves behavioral interventions. Rehabilitation has now become common practice for patients with COPD. However, the components of rehabilitation need additional study. It is unclear whether benefits attributable to intervention result from exercise, compliance with medications, psychosocial support, relaxation training, or some combination of interventions. Further, additional study is required to maintain behavior change over the course of time.

Finally, outcome measurement deserves continuing attention. Benefits of both surgical and medical treatments are often represented as changes in quality of life. In addition, measures of shortness of breath and psychosocial mediators must be validated in continuing studies. A variety of behavioral and psychosocial variables may mediate outcome for patients with COPD, including depression, social support, and self-efficacy expectations. Ultimately, treatments might be tailored to patients with particular psychosocial needs.

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