ADDRESSING BEHAVIORAL AND EMOTIONAL ASPECTS OF COPD*

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ABSTRACT

This article addresses 2 important clinical problems of chronic obstructive pulmonary disease, functional limitations and exacerbations, each with behavioral and emotional elements that can create challenges in clinical practice. The article begins with a model for analyzing a patient's functional status to clarify this important problem and inform more precise diagnosis and treatment. With this model in mind, results from qualitative studies are used to inform a discussion of the behavioral and emotional aspects of functional limitations, from the perspective of the patients themselves. This is followed by a discussion of patient experiences with exacerbation using insights gained through a qualitative study conducted as part of the development of EXACT (Exacerbations of Chronic Pulmonary Disease Tool), a new patient-reported outcome measure for use in clinical trials and natural history studies. ([Adv Stud Med. 2008;8(13):463-468])

FUNCTIONAL LIMITATIONS

A MODEL FOR ASSESSING FUNCTIONAL STATUS AND SELECTING INTERVENTIONS

Functional status has been defined as a multidimensional concept characterizing one’s ability to provide for the necessities of life—that is, those activities people choose to perform in the normal course of their lives to meet basic needs, fulfill usual roles, and maintain their health and well-being. To increase the precision of patient assessment and improve the selection and evaluation of treatment in practice and research, 4 components or dimensions of functional status have been proposed (Figure). Functional capacity refers to...
an individual's maximum potential to perform activities, with maximal physical exertion (usually indexed as VO2 max), 6-minute walk distance, or the shuttle-walk test serving as examples of capacity indicators. It is important to note that people generally do not choose to conduct their lives at capacity on a day-to-day basis, nor could they do so for sustained periods of time. The term functional performance refers to the daily activities people choose to do in the normal course of their lives, subject to limits imposed by capacity. Functional reserve is the difference between capacity and performance and refers to latent or dormant abilities that can be called upon as needed. Finally, functional capacity utilization is the proportion of functional capacity that is called upon in the selected level of performance.

Assessing each of these dimensions can provide useful information about a patient's functional status, with implications for treatment and outcome evaluation. For example, limitations in exercise tolerance or pulmonary function indicate the patient has reduced functional capacity. Patients who report little to no activity in or outside the home have limited functional performance. Those describing dyspnea if they increase their activity are infringing on their reserve, suggesting an increase in capacity may provide relief with the potential for increasing performance. Long-acting bronchodilators can increase functional capacity by improving airflow, thus increasing the patient's reserve, observable in less dyspnea and rescue medication use. Pulmonary rehabilitation programs are designed to increase both capacity and performance by improving muscle strength and endurance. For patients whose capacity is optimized but underutilized, perhaps due to fear associated with increasing their performance, rehabilitation can provide a protected environment in which they can test higher performance levels before initiating additional activities in and around the home.

**PATIENT PERCEPTIONS OF FUNCTIONAL STATUS**

The categories of activities patients with COPD commonly perform are shown in the Table. As a group, patients with COPD report limitations in each of these areas. The extent to which individual patients perform various activities is related to their perceptions of reward and consequences. Specifically, decisions are a function of the personal satisfaction patients have had or expect to derive through an activity, weighed against the discomfort they expect to occur. Satisfaction includes the personal enjoyment associated with an activity or the fulfillment associated with activities that contribute to the welfare of others. If the anticipated satisfaction outweighs discomfort, the activity is performed; when the discomfort, real or anticipated, outweighs the satisfaction, the activity is altered or relinquished altogether. Discomfort takes the form of symptom distress, par-

<table>
<thead>
<tr>
<th>Category</th>
<th>Sample Activities</th>
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</thead>
<tbody>
<tr>
<td>Body care</td>
<td>Showering or bathing</td>
</tr>
<tr>
<td>Household maintenance</td>
<td>Carrying groceries; vacuuming or sweeping</td>
</tr>
<tr>
<td>Movement or exercise</td>
<td>Walking up and down stairs; walks</td>
</tr>
<tr>
<td>Recreation</td>
<td>Going to the movies</td>
</tr>
<tr>
<td>Spiritual activities</td>
<td>Attending services; participating in study groups</td>
</tr>
<tr>
<td>Social activities</td>
<td>Talking on the telephone; playing with grandchildren</td>
</tr>
</tbody>
</table>

COPD = chronic obstructive pulmonary disease.
ticularly dyspnea or cough, and/or the anxiety, frustration, or embarrassment associated with these symptoms. In fact, patients view symptoms as “intruders,” interfering with their ability to lead an enjoyable, satisfying life. They use “enablers,” including planning ahead, pacing, assistive devices, and personal assistance, to help them continue desired activities in the face of discomfort. Over time, as the disease progresses, patients find themselves abandoning the activities that gave meaning to their lives, with some patients “letting go” and moving on to other less demanding activities that also offer satisfaction, whereas others “give up,” with feelings of failure, isolation, and personal futility or uselessness. The depression that often accompanies COPD (Sidebar) may be a function of this process of “giving up,” with a loss of personal integrity as patients become disconnected from others and feel a lack of effectiveness in dealing with their daily lives. These feelings can contribute to a downward spiral of reduced performance, discouragement, and deconditioning that runs its own trajectory, independent of pulmonary function.

**Activity and Exercise**

An important therapeutic goal for patients with COPD is to maintain or improve their functional capacity, particularly their muscle strength, flexibility, and cardiovascular conditioning. It is desirable to recommend a program of exercise, such as walking or biking, for 20 to 30 minutes 3 to 5 times each week and muscle-strengthening activities at least twice a week, with frequency and intensity determined by severity of COPD and other health considerations. Unfortunately, patient compliance with these recommendations is highly variable, with true compliance likely to be substantially lower than reported. Study results discussed earlier provide insight into factors likely to influence patient motivation to exercise and their probability of adherence. If patients find exercise unsatisfying or these routines are not helping them maintain their personal integrity by feeling connected to others or enhancing their effectiveness in their daily lives, particularly in light of the dyspnea, muscle fatigue, or other associated discomforts, patients are likely to choose not to comply with exercise advice which, from the patient’s perspective, is a reasonable decision. On the other hand, if the program is satisfying and enhances personal integrity, patients are more likely to be interested in pursuing the activity initially and sustain it over time. Decline in compliance to exercise regimens following the completion of a rehabilitation program may occur because patients find the independent activity less rewarding or more uncomfortable than exercise performed in a group.

One clinical technique for use with patients reluctant or uninterested in an exercise program or unwilling to participate in rehabilitation is to change the context of the discussion or recommendation from “exercise” to “movement” or “activity.” Getting sedentary patients to move can be an important first step in attempts to regain lost capacity or minimize the rate of decline. The daily activities patients perform as a normal part of their life, including caring for themselves and their families, moving about the home and community, and participating in social engagements, can be fulfilling and at the same time involve activities that, although short of formal exercise, may be therapeutic from muscle strength and joint flexibility as

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**SIDEBAR. Depression in COPD**

*Cynthia S. Rand, PhD*

The evidence overwhelmingly demonstrates that depression is a substantial, substantive comorbidity of chronic obstructive pulmonary disease (COPD). Across the range of chronic illnesses, including cardiovascular disease, diabetes, and COPD, depression is a powerful predictor of increased healthcare utilization and greater mortality. Depression is more common in patients with COPD than in those with other chronic illnesses, such as diabetes or heart disease. Yet most evidence indicates that depression is underdiagnosed and undertreated in COPD. It is essential to aggressively manage depression in COPD because it is an important moderator of people’s willingness to undertake activities and interventions that might benefit them. Physicians who treat these patients need to partner with psychiatrists to effectively implement pharmacologic and nonpharmacologic treatments. Although there is much to be learned about the best way to treat depression in COPD, it has the potential to affect many other aspects of COPD, including quality of life and willingness to undertake activities. People who are depressed do not exercise. They have reduced activity and social interactions. They are less likely to adhere to therapy. And they are also less likely to quit smoking. Depression should be a primary clinical focus—a high-level intervention critical to COPD management, not a secondary consideration.

**Reference**

well as a psychological and motivational perspectives.\textsuperscript{13} The discussion can begin by asking patients to identify several activities they enjoy and want to perform, encouraging them to perform those requiring higher levels of exertion. A pedometer is an inexpensive, easy to use tool that can be used to encourage people to increase their daily activity levels.\textsuperscript{14} Patients establish a baseline over a 2- to 3-day period and develop incrementally greater target levels over time. For some patients, seeing their daily activity as a concrete number will serve as a reminder to move while the reward associated with watching the numbers increase over time may result in greater daily activity, improved capacity, and the potential for higher levels of psychological well-being.

**EXACERBATIONS**

Exacerbations are an important problem for patients with COPD. Similar to functional limitations, exacerbations have behavioral and emotional aspects conducive to insight through qualitative research. Although there are only a limited number of published studies to date, the results of this work show that patients find this aspect of the disease particularly disconcerting. The terms they use when referring to exacerbations include “crisis,” “attack,”\textsuperscript{15} and a “frightening change.”\textsuperscript{16} The high degree of psychological distress is also evident in feelings of panic and dread with onset.\textsuperscript{17}

Qualitative data from 83 patients with COPD participating in focus groups and interviews conducted as part of the EXACT-PRO Initiative (Exacerbation of Chronic Pulmonary Disease Tool—Patient-Reported Outcome) yielded important information on the patients’ perspective of exacerbations, including descriptions of their evolution, essential attributes of the event, cues used to make decisions to seek healthcare, and indicators of severity and recovery.\textsuperscript{18} An increase in the severity of symptoms that lasts several days and interferes with their normal activity together with worry or concern about their lung condition prompts patients to conclude that they are experiencing an event, rather than another “bad day,” and motivates them to seek care.

These patients also described a complete sense of inertia and dramatic drop in activity with exacerbations. They lose interest, motivation, and the ability to perform activities, with more severe exacerbations associated with dramatic reductions in functional performance. Mild exacerbations keep patients indoors, whereas severe exacerbations make walking across the room very difficult and simple personal care activities nearly impossible. These results are consistent with those reported by Kessler et al,\textsuperscript{15} where nearly all (90\%) of the patients in their study ($N = 125$) reported adverse effects in activities of daily living, with half of these patients indicating they required additional help with tasks during exacerbations, nearly half (47\%) reporting that all activities were stopped, and over a third (39\%; $n = 49$) reported being bedridden. Clearly there are behavioral and emotional components to exacerbations in need of clinical consideration.

**CONCLUSIONS**

The behavioral and emotional aspects of COPD are well known. Results from qualitative research provide insight into the patient’s perspective of functional limitations and exacerbations that can be used to inform practice. By understanding the elements of functional status, the types of activities patients perform and why, and the manner and rationale for relinquishing these activities, clinicians can adjust their assessment methods, better understand patient behavior, and target interventions designed to increase motivation and improve adherence to activity programs. Insight into the frightening nature of exacerbations offers an additional parameter for understanding why and when patients are likely to call the clinic for assistance; questioning patients about their functioning can inform estimations of the magnitude of an event and the need for supportive care.

Patients with COPD are struggling to maintain their personal integrity in the face of declining health, with the goal of controlling their disease, rather than having their disease control them. Results of qualitative research can be used to understand COPD from the patient’s perspective and inform programs designed to improve the process and outcome of care.

**DISCUSSION: SLEEP DISTURBANCES AND COPD**

*Dr Brown:* I am very happy that functional limitations have been an area of focus in our discussions. In reality, sleep is the forgotten stepchild here. More
than 50% of patients with COPD report sleep disturbance, especially difficulty sleeping through the night and excessive daytime sleepiness.19-21 Although we are asking patients how far they walk and what activities they perform, how well they sleep at night certainly may impact how much they do during the daytime. Quality-of-life measures frequently show that sleep impairment is often as pervasive as functional impairment in our patients,22-23 but it is likely underrecognized by clinicians. Studies demonstrate that as disease severity increases, patients experience a longer sleep latency, finding it more difficult to fall asleep.24,25 They experience shorter sleep duration and more frequent awakenings compared to patients without disease.24-27

The physiology of sleep disturbance remains unclear. There does not appear to be a greater risk of obstructive sleep apnea in patients with COPD,24,27,28 and administration of nocturnal oxygen therapy does not necessarily improve sleep.24,29 It is clear that the underlying disorder that is responsible for disturbed sleep in this population is an important area for further research.

My personal hypothesis is that patients with COPD are unable to compensate for the normal changes that occur in inspiratory resistance during sleep. A normal person can maintain ventilation during sleep by increasing inspiratory time, but a patient with COPD and expiratory flow limitation may not be able to do that. If they prolong inspiratory time in order to maintain a tidal volume, they shorten expiratory time and potentially develop dynamic hyperinflation during sleep that leads to increased arousal frequency. If they do not prolong inspiratory time, they inhale a smaller tidal volume, which leads to hypoventilation and rises in carbon dioxide. These increases in carbon dioxide also may lead to arousal.

Unfortunately, we do not know what the best intervention to improve sleep in COPD is. Some non-benzodiazepine hypnotics, such as zolpidem and zopiclone, appear to be safe in patients with COPD and do not decrease respiratory drive,30,31 but additional research surrounding efficacy is needed. In addition, it is unclear whether treatment of isolated nocturnal hypoxemia with oxygen therapy is of clinical benefit.32-34 Additionally, treatment with bilevel nocturnal ventilation for hypercapnic COPD with nocturnal hypoventilation also has not been shown to improve lung function, sleep efficiency, or gas exchange when treated for 3 to 12 months.35

REFERENCES

18. Leidy N. The EXAcerbation of Chronic Pulmonary Disease Tool (EXACT): a patient-reported outcome, phase I. Paper


