Fostering Patient Self-Management of COPD

Key Points
1. Healthcare providers play an important role in helping patients learn to actively self-manage their COPD.
2. The core skills needed to become a good self-manager include problem-solving, decision-making, resource utilization, formation of the patient-provider relationship, and taking action.
3. Self-management tasks that are important to patients with COPD include tobacco cessation, medication adherence, establishing an action plan for exacerbations, learning to cope with breathlessness, eating a healthy diet, and following an exercise plan.
4. Self-management programs offer interventions that not only educate but also empower patients and their families by supporting their efforts toward health improvement.
5. Decision-making should be shared between the clinician and the patient and will vary depending on the stage of disease and the individual focus of the patient (e.g., curative vs. healing).

8.1 Introduction

Chronic Obstructive Pulmonary Disease (COPD), like most other long-term health problems, requires more from medical providers than medication management alone. It necessitates a collaborative partnership between patient and provider. Patient understanding of and investment in efforts to manage symptoms can impact disease burden, quality of life, and healthcare utilization. Although the most challenging aspect of chronic disease management is the art of engaging patients in active self-management, many primary care and pulmonary providers receive little training in these skills and feel least prepared for this aspect of their practice.

8.2 Clinician Skills

Clinician skills that foster behavior change are quite important to the overall management of COPD, but are often ignored. Orleans (1988, cited in Prochaska, 1994, p. 62) reported that 66% of medical providers are pessimistic about their patients’ ability to change. This negativism can easily become the biggest obstacle to helping patients change. Patients and medical providers often feel hopeless about their circumstances and their ability to make improvements, which leads to a vicious cycle of poor health
outcomes. Clinicians need a basic understanding of the stages of change, as well as training in strategies such as motivational interviewing, to engage patients in efforts to improve their health. Interventions that are matched to the patients’ readiness for change and help the patients explore their reasons, needs, and ability to change are much more likely to be effective.

In a comprehensive review of COPD self-management, Effing et al. (2012) offer practical tips for stimulating behavior change. Durdock (2010) also provides tips for affecting behavior change in patients with chronic diseases. The following list incorporates their recommendations, which are also summarized in Table 8.1:

1. **Knowledge does not equal motivation.** Knowledge can be a useful tool in helping patients identify a need to change. However, the process of changing behavior happens over time and involves several other key ingredients. Patients need to consider their ability to make a change, how it will impact the lives of others, how they will cope with any losses associated with the change, and where and how the new behavior might fit into their daily lives.

2. **Non-adherence to a treatment plan does not mean the patient does not care.** There may be a number of barriers to accomplishing behavioral goals. Teaching patients to brainstorm alternative strategies and resources is an important skill-building task to address barriers. The skilled clinician will ask open-ended questions to help explore and resolve ambivalence about making a change. Fight the urge to think negatively about a patient who does not seem to put effort towards behavior change. It may be that the patient feels helpless or depressed. The clinician’s attitude can have a profound impact in either reinforcing the patient’s negatively skewed view or providing hope and compassion.

3. **It is the patient’s agenda.** The first question to ask might be, is this the patient’s goal that he or she created? The patient must be the one to set priorities and iden-
tify what is most important for him/her to change. The clinician may feel that quitting smoking is a priority but the patient may select to invest in pulmonary rehabilitation instead. Often success with a smaller, more feasible goal will eventually lead to approaching larger, more challenging goals in the future. Alternatively, the patient may feel overwhelmed and depressed by the debility of the disease and select to invest in psychotherapy first before any other behavior change is feasible. It is important to offer options to patients and to honor their choices.

4. **Spend more time focusing on the positive effects of adaptive behaviors than on the negative effects of poor health choices.** It is tempting to share information about all the dangers of smoking or inactivity. If this is a strong urge, ask the patient what they know about the negative effects first. For many patients, a lack of knowledge is not the problem (see Tip #1). It is more important for the patient to verbalize how life will be better if he/she is able to make the behavior change. The more the patient states his/her reasons, abilities, desires and needs to change, the greater the likelihood that change will occur (Miller, 2013).

5. **Stimulate patient responsibility by asking open-ended questions instead of giving advice or solving the problem for the patient.** Patients are more engaged and activated when asked, “What concerns you the most about COPD and your health in the next five years?” or “What might you do differently to prevent another hospitalization?” It may actually take less clinician time and energy to ask these open-ended questions than to think of two or three ideas for the patient to try, only to hear the response, “No, that’s not feasible for me.”

6. **Help patients formulate action plans that are action-oriented, time-limited and measurable.** Patients just starting to make self-management goals should focus on weekly action plans and would benefit from weekly support. As patients successfully complete weekly action plans, they may be ready to create monthly or quarterly plans. Self-management classes like the Chronic Disease Self-Management Program, Living Well with COPD, Tobacco Treatment classes, and weight management classes are ideal for building this skill and generating success.

7. **Highlight patient self-efficacy by asking them how confident they are on a scale from 1 to 10 (with 10 being the most confident) that they can accomplish their action plan.** Ask what makes it the number given and not a LOWER number. This leads the patient to again vocalize the reasons, abilities, desires, and needs for completing the plan. This repetition may seem like a waste of precious time. However, stating the reasons for change is the most critical factor associated with behavior change (Miller, 2013).

### 8.3 Stages of Change

A patient’s readiness for change is a crucial factor in all health behavior changes. Prochaska and DiClemente (1983) outlined the stages of change in their investiga-
tions of self-changers. They delineated five distinct stages in the Transtheoretical Model of Change (also known as the Stages of Change Model) that all self-changers progress through as they attempt to make a behavioral change. Generally, a person moves from being uninterested, unaware or unwilling to make a change (precontemplation), to considering making a change (contemplation), to deciding and preparing to make a change (preparation), to taking steps and problem-solving challenges or barriers (action), and to incorporating the change into a daily routine (maintenance). Relapses are usually inevitable and become part of the process of working toward permanent change. No matter what behavior is targeted for change, each stage is progressed through. No stage is skipped, although progress is often non-linear. Ambivalence about changes leads people to “recycle” through some stages several times. The Stages of Change model is discussed in more detail in Chapter 7.

8.4 Patient Self-Management Skills

Engaging patients in active self-management starts with Primary Care and often requires more intensive support and guidance from a variety of services to address a number of tasks. Self-management is generally understood as “the day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status” (Clark, 1991, p. 5). Healthcare providers work with their patients to help them develop and sustain self-management. Self-management involves coping with direct physical symptoms and reduced ability as well as the psychosocial problems that may accompany COPD. Clark and colleagues (Clark, 1991) defined three tasks of good self-managers:

1. Have knowledge about the disease and treatment options in order to make informed decisions;
2. Complete tasks aimed at managing the condition;
3. Apply skills to manage psychosocial distress associated with the chronic illness.

The Social Cognitive Theory of self-management emphasizes the development of core skills needed to become a good self-manager (Lorig, 2003). These skills include: problem solving, decision-making, resource utilization, formation of the patient-provider relationship, and taking action. Workbooks and exercises lead patients to build these skills, often in individual case management visits or in patient education classes. Skill mastery is accomplished through completion of short-term action plans. This new competence leads to increased confidence and self-efficacy, which is the belief that one can successfully complete the desired task/behavior (Bandura, 1977). Improved self-efficacy is predictive of lasting behavior change.
8.5 Self-Management Tasks

COPD-specific self-management tasks are a significant part of successful treatment. Zwerink and colleagues (Zwerink, 2014) completed a comprehensive review of COPD self-management studies and identified six tasks that are common to the various self-management curricula: 1) medication adherence, 2) exacerbation action plans, 3) smoking cessation, 4) coping with breathlessness, 5) healthy diet, and 6) exercise plan. A workgroup of COPD self-management experts concurred that all of these tasks except for medication adherence are essential to successful self-management of COPD (Effing, 2012). Table 8.2 depicts the prevalence of each task in the studies reviewed.

Medication adherence, exacerbation action plans, coping with breathlessness, healthy diet, and exercise plans specific to COPD will be discussed in depth in this chapter. Smoking cessation – perhaps the most important self-management task for patients with COPD – is discussed in detail in Chapter 7. Coping with psychosocial distress related to chronic illness is also an important self-management task that will be discussed further in Chapter 13. Energy conservation strategies (e.g., pacing of activities) will be reviewed briefly in this chapter and will be covered in more detail in Chapter 14.

Benzo et al. (2013) recommend offering patients a choice of a variety of self-management options. Graphic representations and worksheets may facilitate the selection process and serve to:
1. Educate the patient about all of the tasks involved in successful COPD self-management;
2. Allow the patient to explore and understand each option to make an informed decision;
3. Provide a worksheet to spell out a specific action plan to initiate change; and
4. Act as a reminder of all of the tasks and the behavioral plan.
Two examples of these agenda-setting tools are My COPD Choices (Figure 8.1) and COPD Self-Management Choices (Figure 8.2).

8.5.1 Medication Adherence

One specific behavior that is unique to COPD and requires special attention is proper inhaler use (see Chapter 15, Correct Inhaler Techniques). Patients are often confused about:

1. Which inhalers to take at what time;
2. The difference between short-acting and long-acting inhalers;
3. Whether a spacer is necessary;
4. How to properly use inhalers to get the most benefit.

Patients’ poor compliance with COPD medications has been documented for decades (Windsor, 1980; Kaplan, 1990; Dolce, 1991; George, 2005; Krigsman, 2007a, b). Across studies, an average of 60% of COPD patients do not adhere to inhaler therapy over time (Chryssidis, 1981; Taylor, 1984; Dompeling, 1992; Bosley, 1994; Krigsman, 2007a,
b; Haupt, 2008) and up to 85% do not use their inhalers correctly (Crompton, 1990; Thompson, 1994; Van Beerendonk, 1998; van der Palen, 1995, 1998; Hesselink, 2001; Serra-Batllés, 2002). The most common self-reported reasons for poor adherence to inhaler use are forgetting (51%) and consciously deciding not to use it when feeling good (31%; Dolce, 1991).

In a review by Restrepo et al. (2008), regular instruction, supervision, and re-demonstration of proper inhaler technique were recommended to improve inhaler adherence. It is well recognized that demonstration and supervised practice with inhalers are far superior to written instruction alone. Another visual aid that can reduce confusion and improve compliance is the Cincinnati VAMC Respiratory Medications Visual Pillbox (Figure 8.3), which displays pictures of all inhalers on the formulary classified by type of inhaler and spacer use if applicable, and denotes dosing schedules. Inhalers prescribed for a particular patient are circled and the dosing times are checked by the provider. The Visual Pillbox is used in conjunction with inhaler demonstrations and practice. To assist with re-teaching, patients waiting to see their provider may be invited to watch videos demonstrating proper inhaler use. Providers can follow up by asking the patient about any differences between their technique and that portrayed in the video. (Correct inhaler use techniques are reviewed in Chapter 15, Practical Guide to Inhaler Use.)
Figure 8.3: Visual Pillbox. The Cincinnati VAMC Respiratory Medications Visual Pillbox is a visual medication aid that can reduce confusion and improve medication adherence. Pictures of all inhalers on the formulary are classified by type of inhaler and spacer use (if applicable) and the dosing schedule is pictorially displayed. Inhalers prescribed for a particular patient are circled and the dosing times are checked by the provider. The Visual Pillbox should be used in conjunction with inhaler demonstrations and practice.
Although improving patient comprehension may be helpful for some, other barriers to compliance should be considered as well. Patients with poor medication compliance are less likely to have a strong sense of faith and trust in their provider, they are more likely to rely on natural remedies, and they have low confidence in treatment effectiveness (George, 2005). To a lesser extent, non-adherence is associated with the complexity of the medical regimen, patient concerns about side-effects, the cost of treatment, and the number of medications the patient is prescribed. Underuse, especially in periods of increased symptoms and respiratory distress, is a common problem that might also be related to depression. Depressed patients are three times more likely to be noncompliant with treatment regimens (DiMatteo et al., 2007).

### 8.5.2 Exacerbation Action Plans

Reduced frequency of hospitalizations has been a major focus in COPD self-management studies. The financial burden of hospitalization is considerable given that 34% of patients are readmitted for respiratory issues within 90 days of discharge (Bucknall, 2012). Initial hospitalization and readmittance may occur because patients have trouble identifying exacerbation symptoms. The subsequent delay in seeking treatment (Rice, 2010; Bourbeau, 2003) increases the need for more intensive treatment, such as hospitalization. Researchers have concluded that exacerbation action plans can help patients become better able to identify symptoms and implement appropriate treatment plans, thereby reducing delays in intervention, preventing or reducing hospital stays, and promoting quicker recovery. Exacerbation action plans have also demonstrated effectiveness for asthma, congestive heart failure, and diabetes (Ofman, 2004).

There is evidence that COPD exacerbation action plans improve health-related quality of life (Zwerink, 2014). A meta-analysis of nine studies indicated that when self-management interventions included an exacerbation action plan, the risk of a respiratory hospital admission was reduced (Zwerink, 2014). Bischoff et al. (2011) concluded that exacerbation action plans were associated with a decrease in the number of days to recovery and associated with reduced healthcare utilization. However, exacerbation action plans did not necessarily reduce hospitalizations (Bischoff, 2011; Trappenburg, 2011), particularly when there was limited follow-up or education about the plans (Walters, 2010). While many studies have shown COPD exacerbation plans to be effective, not all have consistently yielded positive results. In fact, one study was terminated before completion because of a higher rate of death in the intervention group (Fan, 2012). The researchers hypothesized that a theory-based comprehensive care management program, an individualized treatment action plan for worsening COPD symptoms, and telephone case management would reduce the risk of COPD-related hospitalizations for patients who have severe COPD and are at risk for hospital admission. The study was stopped after an imbalance in mortality between the usual
care group and intervention group was discovered. When the study was terminated, 28 patients in the intervention group had died, compared to 10 patients in the usual care group. Despite extensive data analysis, no individual factors or combination of factors plausibly explained the differences in mortality (Fan, 2012).

There are emerging data that outline more specific characteristics of patients who benefit from exacerbation action plans. Gadoury and colleagues (2005) found several patient characteristics that predicted reduced hospitalizations, including being female, having a higher level of education, and increased walking capacity. Bucknall et al. (2012) identified patient activation or readiness for change, younger age, and living with other people as critical factors for patients to be successful self-managers and have fewer hospitalizations.

In sum, the research to date remains fairly inconclusive about the clinical effectiveness of exacerbation action plans. The proposed Department of Veterans Affairs/Department of Defense [VA/DoD] Guidelines for COPD (2014) recommend the use of exacerbation action plans only within the context of close monitoring by providers to ensure supported self-management. As such, treatment effectiveness and successful mastery of the action plan must be assessed continuously to ensure comprehension and adherence. Symptom diaries, enlisting caregiver support, and self-report regarding adherence are possible strategies that will allow the provider to better support the patient’s treatment adherence.

8.5.3 Coping with Breathlessness

Dyspnea, or breathlessness, is a multi-factorial symptom that involves both pathophysiologic and psychosocial factors. A cardinal feature of end-stage COPD, dyspnea can lead to high levels of distress and anxiety. Patients can benefit from having a thorough understanding of the causes of dyspnea (e.g., air trapping) and various self-management strategies they can use to gain a greater sense of control over their breathing. The most effective non-pharmacological treatments for dyspnea include pursed-lip breathing and pulmonary rehabilitation, although other strategies, such as abdominal breathing, yoga, and relaxation techniques, should be discussed to allow patients to decide what works best for them (Allen, 2010; see Chapter 14, Management of Stable COPD). Although a systematic review conducted by Holland et al. (2012) did not find evidence for consistent effects of pursed-lip breathing, abdominal breathing, and yoga on dyspnea or health-related quality of life, participants did experience improvement in exercise capacity.

Among patients with COPD, higher levels of anxiety and depression are associated with increased fatigue, dyspnea, and frequency of respiratory symptoms (Doyle, 2013). Dyspnea may occur in earlier stages of COPD in some patients, usually among females with comorbid anxiety and depression (Di Marco, 2005). Psychotherapy has been found to be useful for the treatment of depression and adjustment to chronic
illness but is not directly effective in addressing dyspnea (Marciniuk, 2011). However, patients hospitalized with COPD exacerbations have demonstrated reductions in dyspnea, depression, and anxiety after learning controlled breathing techniques from a respiratory therapist (Valenza, 2014). Thus, learning to manage breathing independently can help to improve overall quality of life for patients with COPD. See Chapter 13, COPD’s Effects on Psychosocial Functioning and Familial Interactions, for more information about the relationship between depression, anxiety, and COPD.

8.5.4 Exercise

Patients with COPD might find exercise to be too physically difficult to incorporate into their daily routines or they might feel overwhelmed by the amount of time and energy they are already contributing to self-managing COPD. Additionally, dyspnea can limit physical functioning. However, exercise programs, breathing retraining, and breathing exercises have been shown to reduce dyspnea and improve quality of life (VA/DoD, 2014). The proposed VA/DoD Clinical Practice Guideline for the Management of Chronic Obstructive Pulmonary Disease (2014) suggest that supervised exercise programs be provided to patients who have limited physical capabilities due to dyspnea.

Casaburi et al. (1997) investigated the effect of exercise tolerance and physiological responses in patients who have COPD. The researchers found that patients with severe COPD who exercise rigorously and regularly improve exercise breathing patterns and lower ventilation, both of which are associated with improved exercise tolerance. McNamara et al. (2013) suggested aquatic exercise for individuals who feel more comfortable with low-impact exercise. They concluded that aquatic exercise provides as much physical benefit (e.g., improve walking distance) as land-based exercise, and actually improves endurance exercise more than land-based exercise. Leung et al. (2013) determined that Sun-style t’ai chi is an effective moderate exercise for people with COPD, and can result in a number of health benefits (e.g., increased endurance shuttle walk time). For patients who are unable to participate in physical exercise because of dyspnea, the VA/DoD guidelines (2014) recommend offering breathing exercises to patients. One such breathing intervention is inspiratory muscle training (IMT). Inspiratory muscle training focuses on increasing the strength of the inspiratory muscles (e.g., the diaphragm) using a device or pursed lip breathing. Even when used as a stand-alone therapy, IMT is effective in strengthening inspiratory muscles, decreasing symptoms of dyspnea, and improving exercise capacity (Gosselink, 2011; Geddes, 2008). Finally, exercise has been shown to improve mental functioning. Emery et al. (2001) suggest that individuals with COPD have difficulty with fluid intelligence (the ability to take in new material and make sense of it). The researchers determined that just 20 minutes of exercise at peak levels (based on an individual’s heart and breathing rates) improves mental functioning.
8.5.5 Nutrition

Proper nutrition is particularly important for patients with COPD who require more energy than individuals with normal lung functioning to acquire and utilize oxygen (Allen, 2010). Being underweight increases the risk of mortality for patients with COPD (Schols, 1993). Even patients with stable COPD can experience weight loss due to the disease, which highlights the importance of identifying and addressing weight changes quickly and effectively. Nutritional screening should focus on assessing BMI and weight change, the latter of which is defined as weight loss of more than 10% of one’s body weight in the past six months, or more than 5% of one’s body weight in the past month (Celli, 2004). Weight loss (i.e., imbalance between energy expenditure and dietary intake) and muscle wasting (i.e., imbalance between protein synthesis and breakdown) contribute to the disability and mortality experienced by patients with COPD. As such, nutritional interventions may need to be combined with an exercise regimen in order to provide benefit to the patient (Creutzberg, 2003).

Patients should be educated about ways to obtain adequate caloric intake while choosing foods that do not raise carbon dioxide levels (i.e., choosing complex carbohydrates and healthy fats rather than simple carbohydrates and protein). Nutritional recommendations that might be made to all patients, such as watching salt intake, avoiding overeating, and staying hydrated, become particularly important for patients with COPD, whose ability to breathe and expel mucus are strongly impacted by these behaviors. Meal tips that may be beneficial for patients include sitting at the table while eating to encourage good posture and allow the diaphragm to work properly, taking small bites and chewing slowly to prevent overeating, resting before eating to maintain energy during the meal, and drinking fluids at the end of the meal to allow room for food (Allen, 2010).

8.6 Self-Management Programs

There are outstanding resources available to support patients with COPD and the healthcare teams who treat them. Self-management programs specific to COPD include pulmonary rehabilitation and Living Well with COPD (www.livingwellwithcopd.com, 2014). Other self-management programs, including the Chronic Disease Self-Management Program, tobacco treatment, and weight management programs, are also excellent options to empower patients and support their efforts toward health improvement. A few of the above-mentioned programs will be reviewed to address their unique contributions to COPD management.
8.6.1 Pulmonary Rehabilitation

Pulmonary rehabilitation (PR) primarily focuses on building physical strength and endurance through a supervised, graded exercise program that occurs several times per week. The American Thoracic Society (ATS) and the European Respiratory Society (ERS) recently updated their definition of pulmonary rehabilitation (Spruit, 2013, p. e14):

“Pulmonary rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education, and behavior change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors.”

Most PR programs are multi-disciplinary and include weekly education and support sessions to address a number of self-management tasks. Topics may include basic education about COPD and how to manage it, proper medication use, nutrition, energy conservation, coping with difficult emotions, and breathing strategies. There are a number of positive outcomes associated with pulmonary rehabilitation, including reduced dyspnea, increased exercise capacity, and improved quality of life (Spruit, 2013). Similar results were found in a systematic review of 18 randomized clinical trials that focused on home-based programs, which suggests that home-based pulmonary rehabilitation is an acceptable alternative to clinic-based programs (Liu, 2014).

Recent research has also added the following new advances (Spruit et al., 2013, p. e14):

– There is increased evidence for use and efficacy of a variety of forms of exercise training as part of pulmonary rehabilitation; these include interval training, strength training, upper limb training, and transcutaneous neuromuscular electrical stimulation.
– Symptomatic individuals with COPD who have lesser degrees of airflow limitation and participate in pulmonary rehabilitation derive similar improvements in symptoms, exercise tolerance, and quality of life as do those with more severe disease.
– Pulmonary rehabilitation initiated shortly after a hospitalization for a COPD exacerbation is clinically effective, safe, and associated with a reduction in subsequent hospital admissions.
– Exercise rehabilitation commenced during acute or critical illness reduces the extent of functional decline and hastens recovery.
– Appropriately resourced home-based exercise training has proven effective in reducing dyspnea and increasing exercise performance in individuals with COPD.
– The scope of outcomes assessment has broadened, allowing for the evaluation of COPD-related knowledge and self-efficacy, lower and upper limb muscle function, balance, and physical activity.
– Symptoms of anxiety and depression are prevalent in individuals referred to pulmonary rehabilitation, may affect outcomes, and can be ameliorated by this intervention.
8.6.2 Living Well with COPD

Living Well with COPD is a self-management program that teaches patients with COPD the skills necessary to manage their illness in a collaborative environment designed to enhance self-efficacy and motivation for change. The goal of Living Well with COPD is to “develop a partnership between patients and healthcare professionals to facilitate the adoption of healthy lifestyle behaviors and the skills needed to better manage COPD on a day-to-day basis” (Nault, 2006). Drawing from the chronic care model (Wagner, 2001), the Chronic Disease Self-Management Program (Lorig, 2003), and the Precede-Proceed Model (Green, 1999), Living Well with COPD provides educational interventions that are tailored to the learning needs of individual patients and are designed to enhance self-efficacy, increase motivation to create and maintain behavioral change, and facilitate mastery of self-management skills. The objectives of the program are to help patients improve quality of life, maximize autonomy, prevent and manage progression of the disease, and help caregivers support the patients’ efforts to achieve behavioral change.

Living Well with COPD can be completed on a weekly basis in individual sessions, a group setting, or as part of a pulmonary rehabilitation program. The program consists of seven skill-oriented modules that provide detailed information related to self-management of various facets of COPD (e.g., medication compliance, controlling breathlessness, prevention and management of exacerbations). The patient education process requires that the educator utilize the following steps:

1. Assessment of readiness and motivation to learn,
2. Setting mutually realistic learning goals and objectives,
3. Use of efficient educational methods,
4. Implementation of educational objectives, and
5. Evaluation of patients’ learning outcomes (e.g., direct questioning, problem solving, repetition of key instructions).

Effective provision of the Living Well with COPD program requires that the provider (i.e., any health care professional willing to devote time to this process) have both expertise regarding proper management of COPD as well as empathy and enthusiasm for the patients and their journey toward effective COPD self-management through long-term behavior change. (Patients and providers can learn more about the program at www.livingwellwithcopd.com.)

Utilization of the Living Well with COPD program yields positive outcomes. In a one-year, multi-site, randomized clinical trial, the program improved quality of life, reduced hospitalizations and emergency department visits for COPD exacerbations by 40%, and decreased unscheduled medical visits by nearly 60% (Bourbeau, 2003). Another one-year, multi-site, randomized clinical trial conducted by Gadoury et al. (2005) found that participants of the Living Well with COPD program continued to demonstrate reductions in all-cause hospitalizations (27%) and all-cause emergency visits (21%) at the end of a two-year follow-up period.
8.6.3 Chronic Disease Self-Management Program

Disease-specific education is necessary but not sufficient to produce patient actions related to managing the disease (Becker, 1980). Becoming a better self-manager is linked to learning how to set goals, organize resources, and use problem-solving strategies (Clark, 1991). Bodenheimer et al. (2002) indicated that self-management classes that included action planning were more likely to improve health outcomes, particularly for participants with more severe symptoms.

The Chronic Disease Self-Management Program (CDSMP), which was created by Kate Lorig, Virginia Gonzalez, and Diana Laurent, focuses on developing self-management skills needed to manage effectively any chronic health condition by teaching goal-setting, problem-solving, and action planning (Lorig, 2012). This structured treatment, led by healthcare professionals and/or lay leaders, is unique in its ability to address a number of health problems in one group format. Patients with comorbid chronic conditions can benefit from the patient education approach, which focuses on improving breathing, healthy eating, physical activity, medication usage, dealing with difficult emotions, relaxation strategies, positive thinking, and communication skills. However, the true lasting benefit from the program is the skill building that takes place around brainstorming, problem solving, and action planning. Each class incorporates an opportunity to brainstorm, a process where ideas are quickly generated without being questioned or censored to allow for the most creative and extensive list possible. Participants also learn and practice a problem-solving method that encourages them to consider and try alternative strategies, which provides a greater sense of control and improves investment in care.

Action planning in CDSMP helps participants work toward goals of their choice during and between each class. Participants may choose any goal, as long as it meets the criteria listed in Table 8.3 (Lorig, 2001). Initially, participants may struggle to meet all these criteria, perhaps choosing things that will not fit into their schedule, are more strenuous than they can handle, or involve resources they may not have. The group is utilized to brainstorm ways to make the plan more specific or practical and build the participants’ confidence in their ability to succeed. The following session involves progress reports and brainstorming by the group to identify strategies that can make the goal more feasible. Through this process, participants learn to make action plans that they can accomplish. They build on small successes and become more confident in their ability to feel in control of their symptoms and their lives.

Lorig et al. (2001) conducted a two-year follow-up study that looked at health status, health care utilization and self-efficacy outcomes for 831 participants 40-years or older with heart disease, lung disease, stroke, or arthritis. Participants who completed at least four of six CDSM sessions had significantly fewer ER and outpatient visits, declines in self-reported health distress, and improvement in perceived self-efficacy. Bodenheimer et al. (2002) reported that patients attending self-management classes had fewer hospitalizations over a six-month period compared to con-
Shared Decision-Making

Shared decision-making is the clinical process that occurs when providers share treatment options, including risks and benefits, and patients weigh their options based on their values and beliefs. While shared decision-making might be most critical when considering end-of-life care, it should be a vital part of all stages of chronic disease management. Clinicians provide the expert information about treatment options, risks, and benefits. Patients feel empowered to use the information to make the choices that fit them best.

Shared decision-making is supported by a focus on whole person care (Hutchinson, 2011), which broadens the scope of clinical interactions to include all aspects of the patient’s life, including physical, emotional, and spiritual factors. A whole person assessment expands beyond a physical exam to include conversations about supportive relationships, meaningful activities, stable safe housing, physical activity, healthy eating, stress and sleep, and active involvement in medical care. This process offers the opportunity for patients and providers to gain a full picture of all aspects of life and how they interact. Creating this unique perspective of one’s life allows the patient to see strengths and areas in which progress is being made. Patients may also start

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<th>Table 8.3: Elements of Patient-Selected Goals During Action Planning in the Chronic Disease Self-Management Program</th>
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<td>– Something YOU (the patient) want to do</td>
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<td>– Achievable</td>
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<td>– Action-specific</td>
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<td>– Answers the questions:</td>
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<td>1. What?</td>
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<td>2. How much?</td>
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<td>3. When?</td>
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<td>– Level of confidence in your ability to complete your action plan</td>
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trols. Healthcare utilization cost savings of the program have been estimated between $390–$750 per year per participant (Lorig, 2001; Boedenheimer, 2002).

Ongoing engagement in self-management is critical to maximizing health, wellness, and independence. The Chronic Disease Self-Management Program is one tool that effectively engages patients and helps them recognize and become actively engaged in their care.
to make connections between areas of difficulty and prioritize areas that still need to be addressed. See Figure 8.4 (*Cincinnati VAMC Personalized Health Plan Wheel of Health*) for an example of a document that can be used to facilitate a whole person assessment.

Chronic disease management calls upon the medical provider and the patient to choose between two areas of focus: curative or healing (Hutchinson, 2011) (Table 8.4). Patients who seek a cure are focused on survival and maintaining all things in life prior to disease onset, which leads to efforts to avoid change, whether adaptive or maladaptive. Patients seeking a cure often have an external locus of control and feel powerless to improve their situation. They look to medical professionals to “fix” the problem. Those seeking a cure are in the precontemplation stage of change and often use defense mechanisms such as externalizing, blame, and denial. Alternatively, patients who are able to shift to a healing perspective are accepting of change. They develop a new identity and are able to recognize that their own actions and efforts can
help them obtain functional improvement and satisfaction. The shift from a curative focus to a healing focus is commonly referred to as *adjustment to chronic illness*.

The role of the provider varies depending on whether the patient is in “curing” mode or “healing” mode. If the patient is focused on finding a cure, the provider can use scientific knowledge to assess symptoms and arrive at a diagnosis. The focus is on the use of algorithms, symptom constellations, physical exam, and test results. Evidence-based treatments are prescribed. When the patient is focused on “healing” – or palliative care – a collaborative patient-provider relationship is necessary. Rather than directing an assessment using an algorithm, the provider can offer treatment options but follow the patient’s wishes as the patient shares what he/she would like to change, how important the change is, and how he/she would like to make it. A team approach is often most effective and fosters an environment of support and guidance that is important for behavioral changes. This whole person approach relieves suffering and promotes healing, particularly in COPD care. The process helps foster a sense of wholeness and balance. Patients identify what really matters in their lives, and clinicians use this information to better align the patients’ health goals and behaviors with their priorities.

Of note, as disease severity increases, the treatment often shifts from being patient-driven to provider-driven. In the early stages of COPD, patients are physically able to invest in exercise programs and self-management classes, which reduces disease burden and improves functioning. Having a positive attitude about patients’ ability and desire to improve is critical during this phase. Adjustment to disease, readiness for change, anxiety, and depression are all possible complicating factors that may make behavior change more challenging. A perspective of whole person

## Table 8.4: Curative and Healing/Palliative Areas of Focus for Providers and Patients

<table>
<thead>
<tr>
<th>Curative</th>
<th>Healing / Palliative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient:</strong></td>
<td><strong>Provider:</strong></td>
</tr>
<tr>
<td>- Is focused on survival</td>
<td>- Uses scientific knowledge to assess symptoms and diagnosis</td>
</tr>
<tr>
<td>- Is focused on maintaining “pre-diagnosis” life</td>
<td>- Focuses on symptom constellations, physical exam and test results</td>
</tr>
<tr>
<td>- Feels powerless to improve situation</td>
<td>- Prescribes treatments</td>
</tr>
<tr>
<td>- Looks to health care professionals to fix it</td>
<td>- Provider:</td>
</tr>
<tr>
<td>- Externalizes, blames, denies</td>
<td>- Follows patient’s lead</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Patient:</strong></th>
<th><strong>Provider:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Accepts change</td>
<td>- Offers treatments based on patient’s preferences</td>
</tr>
<tr>
<td>- Develops new identity</td>
<td>- Works within a team</td>
</tr>
<tr>
<td>- Recognizes power in situation</td>
<td>- Uses a <em>whole person approach</em></td>
</tr>
</tbody>
</table>
health, including physical, emotional, and spiritual health, can help to identify these potential barriers and lead patients to appropriate resources. As COPD progresses, physical limitations increase, and other comorbid conditions impact health, patients become more reliant on medical providers for direction and support. Again, anxiety and depression may develop as patients develop fears about dying and feel that their situation is hopeless.

### 8.8 End-of-Life Discussions

Advanced stages of COPD require a shift in care choices to address end-of-life issues. The primary care provider is often identified as the most appropriate person on the healthcare team to initiate this discussion. Timing of the discussion may be difficult to gauge. The American Thoracic Society recommends that it take place when the patient is stable rather than during an acute exacerbation or hospitalization (American Thoracic Society, 2014). Lanken et al. (2007) argue that palliative care discussions are appropriate anytime there is an exacerbation of symptoms. Discussions about restorative measures are likely to occur simultaneously with options for palliative care.

Curtis et al. (2004) reported that only about a third of patients with COPD discuss end-of-life choices with their primary care provider. As compared to patients with other life-threatening illnesses like cancer and HIV, COPD patients are less satisfied with the information they receive from their healthcare provider about COPD, its course, and end-of-life planning (Curtis, 2004). One complicating factor for providers is the large variability of decline. Patients with very severe impairment can live an average of three years (Celli, 2004), adding to the challenge of when to initiate the end-of-life discussion.

Au et al. (2011) found that COPD patients want to know how long they have to live and what dying might be like and they would like their providers to ask them about their religious beliefs and their feelings about disease progression. While this discussion is best initiated by the primary care provider, it is clearly a topic about which all members of the integrated care team should be well informed and prepared to address. The discussion is likely to happen over a series of visits with different members of the team. It is worthy of revisiting after acute episodes, whether hospitalization was necessary or not. Au et al. (2011) suggest that providers create a standard statement that might help initiate the end-of-life conversation (e.g., “This is something I talk about with all my patients to make sure I understand their wishes.”). Core skills of motivational interviewing, reflections, and open-ended questions are useful to explore and clarify the patient’s preferences, values, and wishes. Examples of standard statements and open-ended questions can be found in Table 8.5. (See Chapter 19, Palliative Care and Hospice, for more information about end-of-life issues.)
8.9 Integrated Care Teams

All self-management studies of COPD agree that a multifaceted approach from an integrated care team is most effective. Wagner (1998) supports an integrated team approach in his Chronic Care Model. His model focuses on Primary Care as the hub and the patient-provider relationship as critical to health improvement. Across studies, key ingredients of services tend to vary, making it difficult to discern whether an ideal combination exists. Patient preference and disease severity are two factors that might impact the options for integrated team members/services. Table 8.6 outlines possible available options and attempts to categorize the service based upon disease severity and the addressed needs and skills. These suggestions are based on the COPD Specialty Care Neighborhood Project at the Cincinnati VAMC (2011–2014).

8.10 Conclusion

Effective self-management of COPD requires active collaboration between the provider and the patient. This alliance will help facilitate patient understanding of and investment in effective disease management which can impact disease burden, quality of life, and healthcare utilization. Self-management strategies should focus on tobacco cessation, medication adherence, establishing an exacerbation action plan (with close monitoring) to intervene early and prevent full-blown exacerbations and hospitalizations, using effective breathing techniques, eating a healthy diet, and following an exercise plan. Patients can benefit from a variety of self-management programs (e.g., pulmonary rehabilitation, Living Well with COPD, Chronic Disease Self-Management Program) that are designed to provide education about COPD, increase motivation to create and maintain behavioral changes, and teach skills necessary to problem-solve when barriers to effective symptom management arise. Providers should utilize strategies to stimulate and support behavior change in patients by maintaining awareness of how a patient’s stage of change and approach to managing chronic illness (i.e., curative or healing) are individually and collectively impacting the patient’s self-management behaviors. By taking a whole person approach to treatment, providers can help patients feel empowered by their strengths and recognize the areas in which

Table 8.5: Examples of Motivational Interviewing Standard Statements and Open-Ended Questions

- “What concerns you the most about dying?”
- “Where would you like to be and who will be with you when you die?”
- (after discussing treatment options) “What treatment options would you prefer?”
- “If you could be assured of one thing about dying, what would it be?”
Table 8.6: Effect of COPD Severity on Skills Offered by Integrated Team Members/Services

<table>
<thead>
<tr>
<th>Disease Severity</th>
<th>Type of Service</th>
<th>Skill Building Offered</th>
</tr>
</thead>
</table>
| 1–4              | Primary Care Provider | 1. Diagnoses  
|                  |                  | 2. Medication management  
|                  |                  | 3. Referral for self-management |
| 1–3              | RN Care Manager in Primary Care | 1. Inhaler teaching  
|                  |                  | 2. Individualized self-management training for COPD  
|                  |                  | 3. Transitions of care – Inpatient, Primary Care, Pulmonology  
|                  |                  | 4. Referral to self-management  
|                  |                  | 5. Monitoring of exacerbation action plan |
| 1–3              | Clinical Pharmacist | 1. Initial inhaler teaching  
|                  |                  | 2. Individualized self-management training for COPD |
| 1–2              | Chronic Disease Self-Management Classes Ex., Living Well with COPD, Chronic Disease Self-Management Program | 1. Problem-solving  
|                  |                  | 2. Action planning  
|                  |                  | 3. Decision-making  
|                  |                  | 4. Partnering with providers  
|                  |                  | 5. Building self-efficacy |
| 1–2              | Other Related Self-Management Programs Tobacco Treatment Weight Management Classes | 1. Action planning  
|                  |                  | 2. Building self-efficacy |
| 1–2              | Telephone Support, Text Support, Secure Email and Mobile Apps for Self-Management | 1. Action planning  
|                  |                  | 2. Problem-solving  
|                  |                  | 3. Building self-efficacy  
|                  |                  | 4. Maintaining improvements long-term |
| 1–2              | Shared Medical Appointment for COPD | 1. Medication management  
|                  |                  | 2. Inhaler teaching  
|                  |                  | 3. Symptom management  
|                  |                  | 4. Action planning |
| 2–3              | COPD Case Manager in Pulmonary Clinic | 1. Inhaler teaching  
|                  |                  | 2. Individualized self-management training for COPD  
|                  |                  | 3. Symptom management  
|                  |                  | 4. Transitions of care – Inpatient, Primary Care, Pulmonology  
|                  |                  | 5. Monitoring of exacerbation action plan |
| 2–3              | Home Telehealth Nurse for COPD | 1. Adherence to medication  
|                  |                  | 2. Problem-solving  
|                  |                  | 3. Decision-making  
|                  |                  | 4. Action planning  
|                  |                  | 5. Symptom management |
**Table 8.6: Effect of COPD Severity on Skills Offered by Integrated Team Members/Services**

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| 1–4              | Primary Care Provider | 1. Diagnoses  
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| 1–3              | RN Care Manager in Primary Care | 1. Inhaler teaching  
2. Individualized self-management training for COPD  
3. Transitions of care – Inpatient, Primary Care, Pulmonology  
4. Referral to self-management  
5. Monitoring of exacerbation action plan |
| 1–3              | Clinical Pharmacist | 1. Initial inhaler teaching  
2. Individualized self-management training for COPD |
| 1–2              | Chronic Disease Self-Management Classes Ex., Living Well with COPD, Chronic Disease Self-Management Program | 1. Problem-solving  
2. Action planning  
3. Decision-making  
4. Partnering with providers  
5. Building self-efficacy |
| 1–2              | Other Related Self-Management Programs Tobacco Treatment Weight Management Classes | 1. Action planning  
2. Building self-efficacy |
| 1–2              | Telephone Support, Text Support, Secure Email and Mobile Apps for Self-Management a | 1. Action planning  
2. Problem-solving  
3. Building self-efficacy  
4. Maintaining improvements long-term |
| 1–2              | Shared Medical Appointment for COPD b | 1. Medication management  
2. Inhaler teaching  
3. Symptom management  
4. Action planning |
| 2–3              | COPD Case Manager in Pulmonary Clinic | 1. Inhaler teaching  
2. Individualized self-management training for COPD  
3. Symptom management  
4. Transitions of care – Inpatient, Primary Care, Pulmonology  
5. Monitoring of exacerbation action plan |
| 2–3              | Home Telehealth Nurse for COPD c | 1. Adherence to medication  
2. Problem-solving  
3. Decision-making  
4. Action planning  
5. Symptom management |
they can take more responsibility for their own well-being. Providers can also engage patients in discussions about end-of-life care to ensure that patients have the opportunity to receive answers to their questions and to express their wishes.

### 8.11 Summary Points

1. Learning specific skills (e.g., problem-solving, resource utilization, taking action) can help patients feel more confident in their ability to initiate and maintain long-term behavioral change.

2. While tobacco cessation is perhaps the most important self-management task, patients who effectively manage COPD also succeed in implementing other self-management strategies (e.g., medication adherence, using an action plan for
exacerbations, learning to cope with breathlessness, eating a healthy diet, and following an exercise plan).

3. Behavior change is a complex process that occurs over time. Self-management programs, such as pulmonary rehabilitation, Living Well with COPD, and the Chronic Disease Self-Management Program offer more intensive support, skill building, and translation of skills to everyday life.

4. Clinicians should have a basic understanding of the stages of change in order to match interventions to the patients’ readiness for change which is clarified through exploration of the patient’s motivations, needs, and abilities.

5. Collaborative end-of-life discussions involving the patient and family members should be conducted in a way that respects the patient’s current stage of acceptance but also calls attention to the importance of making end-of-life decisions as early as possible.

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Personalized Health Plan Wheel of Health. (2014). Cincinnati Veterans Affairs Medical Center, Cincinnati, OH.


*COPD Specialty Care Neighborhood Project.* (2014). (Unpublished). Cincinnati Veterans Affairs Medical Center, Cincinnati, OH.


